

headandneck 5000

Data Manual

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1 Introduction

This data manual is intended to support the use of data from the Head and Neck 5000 study (H&N5000). It includes an overview of the study methodology, the structure of the H&N5000 dataset and a description of all data which are available to collaborating researchers. The information contained in this data manual is for descriptive purposes only and should not be reported in research papers. All data included in research papers should be generated directly from the H&N5000 datasets.

1.1 Background to the Head and Neck 5000 study

Full details of the H&N5000 study can be found at <http://www.headandneck5000.org.uk/>. In brief, the H&N5000 study is a prospective clinical cohort of approximately 5,000 people with head and neck cancer. It brings together clinical data, patient-reported outcomes and biological samples in a single co-ordinated resource for translational and prognostic research. Recruitment into the study began on 4th April 2011 and was completed on 31st December 2014.

1.1.1 Study Aim and Objectives

The justification for setting up this study was to evaluate the outcome of centralisation in head and neck cancer services.

The initial aim of the H&N5000 study was to recruit a clinical cohort of 5,000 people with head and neck cancer and then follow up this cohort for two years. Specifically, the objectives were to:

1. Compare morbidity and mortality outcomes across different centres.
2. Compare quality of life outcomes across different centres.
3. Describe the individual economic cost of head and neck cancer care.
4. Identify prognostic indicators for head and neck cancer.
5. Create a resource for translational and applied research in head and neck cancer.

1.1.2 Recruitment

Participants were recruited from 76 study sites across England, Scotland and Wales. Every new person seen or discussed at the Multidisciplinary Team (MDT) meeting or clinic was eligible for inclusion into the study including those enrolled in other observational studies or trials. The following exclusion criteria were applied:

1. People who are considered to meet the criteria for mental incapacity or vulnerability set out in the mental capacity/vulnerable adult act
2. People who do not have cancer of the head and neck
3. People who have a recurrence of their cancer of the head and neck rather than a new diagnosis
4. People with lymphoma
5. People with a secondary head and neck tumour.

1.1.3 Timeline of data collection

Data collection was undertaken at 3 timepoints:

1. Stage 1 - Baseline

Biological samples collected and clinical data recorded using Data Capture Forms (DCFs). 4-page nurse administered questionnaire and 10-page self completed questionnaire.

2. Stage 2 - 4-months

DCF + 14-page self completed questionnaire.

3. Stage 3 - 12-months

DCF + 16-page self completed questionnaire and a 5-page self completed questionnaire for people that received radiotherapy.

People that were enrolled in the study at the Bristol centre completed an additional 12-page self completed questionnaire (Your Quality of Life, Difficulties in Your Life, Your Appearance) at baseline, 4-months and 12-months.

Figure 1: Overview of data collection

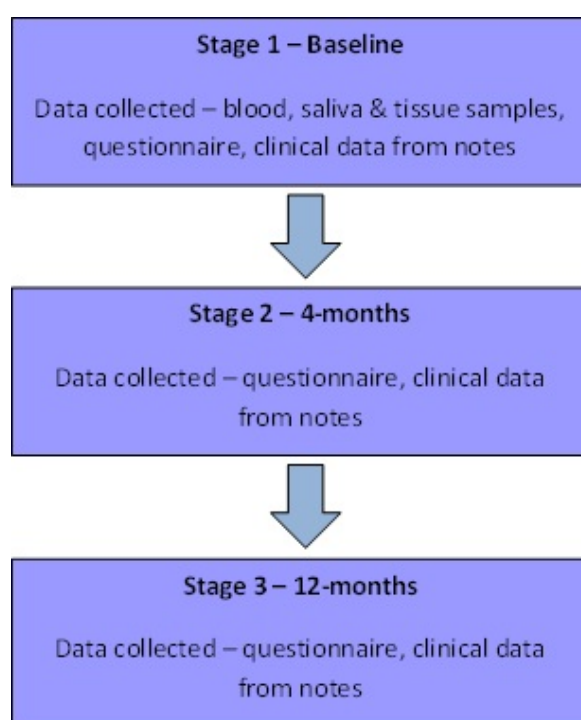


Table 1: Data collection timeline

	Baseline	4 months	12 months
Clinical Data			
Clinical Samples	✓		
Clinical data from notes	✓	✓	✓
Questionnaires			
About You	✓	✓	✓
Your Outlook	✓	✓	✓
Your General Health	✓	✓	✓
Specific Aspects of Your Health	✓	✓	✓
Your Feelings	✓	✓	✓
Your Diet	✓	✓	✓
You and Cancer		✓	✓
Your Personal Costs		✓	✓
Your Quality of Life ¹	✓	✓	✓
Difficulties in Your Life ¹	✓	✓	✓
Sexual History	✓		
Your Appearance ¹	✓	✓	✓
Your Symptoms ²			✓

¹These questionnaires were administered to participants from Bristol only.

²For people that receive radiotherapy only.

Table 2: Details of questionnaires used

Questionnaire	Code ³	Research Topic	Ref
<i>About You</i>	ay	Education, occupation Income EQ5D Smoking, alcohol	(Lagiou et al., 2009) (Benzeval et al., 2009) (Brooks et al., 2003) (The Million Women Study Collaborative Group, 1999; Sitas et al., 2013)
<i>Your Outlook</i>	yo	Revised Life Orientation Test (LOT-R)	(Scheier et al., 1994)
<i>Your General Health</i>	ygh	EORTC QLQ-C30	(Aaronson et al., 1993)
<i>Specific Aspects of Your Health</i>	sayh	EORTC QLQ-H&N35	(Bjordal et al., 1993)
<i>Your Feelings</i>	yf	Hospital Anxiety and Depression Scale (HADS)	(Zigmond and Snaith, 1983)
<i>Your Diet</i>	yd	Three items (fruit, vegetables and deep fried food) modified from the semi-quantitative Food Frequency Questionnaire	(Willett et al., 1985)
<i>You and Cancer</i>	yc	Fears of Recurrence	(Humphris and Ozakinci, 2008)
<i>Your Personal Costs</i>	ypc		Survey designed by Dr. Melissa Ke
<i>Your Quality of Life</i>	yql	The revised University of Washington (UW) QoL Questionnaire	(Hassan and Weymuller, 1993; Rogers et al., 2002)
<i>Difficulties in Your Life</i>	dyl	The Social difficulties Inventory (SDI)	(Wright et al., 2005)
<i>Your Appearance</i>	ya	The Derriford Appearance Scale (DAS 24)	(Carr et al., 2005)
<i>Your Symptoms</i>	ys	Head and Neck Radiotherapy Questionnaire (Late Toxicity)	(Ho et al., 2009)
<i>Sexual History</i>	sh	Sexual History	(Castellsague et al., 2002)

³Questionnaire codes are used in the variable naming convention, please refer to the following section.

1.2 Structure of the Data Manual and Dataset

1.2.1 Data manual structure

The data manual is organised in the chronological order in which the data were collected. Within each data collection time point the documentation is ordered as follows:

- DCFs
 - DCF data were collected from medical records.
- Questionnaires
 - Questionnaire packs contain multiple questionnaires. These questionnaires are documented in the order in which they were presented to participants.

Where new variables have been derived from multiple variables these are documented at the end of the relevant time point and include the associated Stata syntax.

1.2.2 Dataset structure

The H&N5000 datasets contain 3 main groups of variables:

1. **Tracker variables** - variables used to track participants' continued participation in the study and whether they have returned questionnaires
2. **Primary variables** - these are the main variables and relate to questionnaire responses or data recorded through DCFs
3. **Derived variables** - variables which are derived from one or more primary variables

1.2.3 Variable naming convention

Tracker variables are named individually, refer to Section 2 ('Tracker data') on page 17 for details.

Primary variables use the following naming convention:

- *'time point' _ 'question number' _ 'questionnaire code' _ 'text description'*
 - The 'questionnaire code' refers to the codes included in Table 2 on page 12.
 - The 'questionnaire code' 'cb' refers to data collected through the DCFs.
 - The 'text description' may comprise one or more words or an abbreviation to help identify variables. However, the 'text description' component of the variable naming scheme is not needed to uniquely identify variables.

The 'time point' components are labelled as follows:

- **hn1** - Denoting variables which were measured at baseline.
- **hn2** - Variables which were measured at 4-months.
- **hn3** - Variables which were measured at 12-months.

For example - *'hn1_na1_cb_date'* denotes a date recorded at baseline on the data capture form in question A1. The names of variables which are recorded at multiple timepoints differ by their 'time point' component only.

Note: there may be deviations from this naming scheme, please ensure you refer to the variable descriptions provided in this Data Manual and the variable names in the associated dataset.

Derived variables use the following naming convention:

- *'time point' _dv_ 'text description'*

For example - *'hn1_dv_bmi'* denotes a derived variable for BMI (Body Mass Index) recorded at baseline.

1.3 Other information

1.3.1 Data access policy

The data access policy can be found at <http://www.headandneck5000.org.uk/>.

1.3.2 Funder statement

This research has been funded by the National Institute for Health Research (reference number RP-PG-0707-10034).

1.4 Study population

Study participants were recruited from 76 study sites:

Table 3: H&N5000 Study sites

Site name (abridged)	
Aintree	North Cumbria
Barnet & Chase Farm	North Devon
Basildon	Northampton
Bath	Northwick Park
Birmingham Heartlands	Nottingham
Birmingham Queen Elizabeth	Oxford
Boston	Pennine
Bradford	Plymouth
Cambridge	Poole
Chelmsford	Portsmouth
Cheltenham	Rhyl
Chesterfield	Rotherham
Christie	Royal Berkshire
Colchester	Royal Blackburn
Coventry	Royal Glamorgan
Darlington	Royal Gwent
Doncaster	Royal Marsden Chelsea
Dundee	Royal Marsden Sutton
East Grinstead	Royal Preston
Exeter	Royal Surrey
Fife	Royal Sussex
Glasgow	Sheffield
Gloucester	Shrewsbury
Grimsby	South Tees
Hereford	Southend
Hull & E Yorks	Southmead
Imperial	St Georges
Ipswich	Stevenage
Kent & Canterbury	Stoke
Leeds	Sunderland
Leighton	Taunton
Lincoln	Torbay
Luton	UCLH
Maidstone	UH Bristol
Manchester Royal	UH Wales
Mount Vernon	Walsall
Newcastle	Wolverhampton
Norfolk	York

2 Tracker data

2.1 Data received and entered, and withdrawals

Total recruited and confirmed eligible = 5369.

	No.
intBaselineDCFEntered - BL DCF data entered into database	
1 - Yes	5369
intBaselineAboutYouEntered - BL About You data entered into database	
1 - Yes	4019
intBaselineQEntered - BL Questionnaire Data entered into database	
1 - Yes	4038
intBaselineSexHistEntered - BL Sexual History data entered into database	
1 - Yes	3406
int4MDCFEntered - 4M DCF data entered into database	
1 - Yes	5357
int4MQEntered - 4M Questionnaire data entered into database	
1 - Yes	3309
int12MDCFEntered - 12M DCF data entered into database	
1 - Yes	5127
int12MQEntered - 12M Questionnaire data entered into database	
1 - Yes	2806
Withdrwl_BaselineQ - Withdrawn from Baseline Questionnaire	
0 - No	5334
1 - Yes	35
Withdrwl_4MQ - Withdrawn from 4 Month Questionnaire	
0 - No	5295
1 - Yes	74
Withdrwl_12MQ - Withdrawn from 12 Month Questionnaire	
0 - No	5276
1 - Yes	93

2.2 Mortality data

* Mortality

ysnPatientDead

ysnPatientDead	No.	Col %
0 - Alive	4001	74.5
1 - Dead	1368	25.5
Total	5369	100.0

Notes: The deaths recorded in this variable are a combination of notifications from study sites and data from the Medical Research Information Service (MRIS). Details on cause of death are available on request.

3 Stage 1 - Baseline

3.1 Data Capture Form

3.1.1 Section A - Basic Data

In order to protect the confidentiality of participants the following date variables are not available. Variables have been derived (see the appropriate 'Derived variables' sections) which describe participants' age at events including their dates of referral and diagnosis. These variables can be used to define timelines for participants.

1 Date of consent (*hn1_na1_cb_date*)

2 Date of birth (*hn1_na2_cb_dob*) - Please use 'Age at date of consent to nearest year' (*hn1_dv_age*)

3 Date of referral (*hn1_na3_cb_dor*) - Please use 'Days from consent to referral' (*hn1_dv_ref_age*)

4 Date of Diagnosis (*hn1_na4_cb_diagn*) - Please use 'Days from consent to date of diagnosis' (*hn1_dv_diag_age*)

7 MDT treatment decision date (*hn1_na7_cb_mdt_date*) - Please use 'Days from consent to MDT decision date' (*hn1_dv_mdt_age*)

5a Primary Diagnosis

hn1_na5a_cb_primary_icd

- **Data check**
 - ICD codes were compared against ICD10 reference to ensure codes were entered in a compatible format.
 - Codes were checked against Histology results and treatment plan intent to ensure consistency of tumour site.
 - **Used to derive**
 - Tumour location - (hn1_ICD_group)
 - Final pre-treatment staging - (hn1_TNM_stage)
 - **Descriptives:**
-

5b Primary Diagnosis: text description

hn1_na5b_cb_primary_desc

- **Data check**
 - Text fields were used to complete missing values for ICD codes.
 - **Used to derive**
 - Tumour location - (hn1_ICD_group)
 - Final pre-treatment staging - (hn1_TNM_stage)
 - **Descriptives:**
-

Notes: – These variables have not been documented in this data manual. However, they have been cleaned to ensure a consistent coding scheme and were used to derive other variables (see ‘Used to derive’ above). The data for these unprocessed variables are available on request.

6a Histology*hn1_na6a_cb_histology*

- **Data check**
 - Histology codes were compared against reference to ensure codes were entered in a compatible format.
 - Codes were checked against Primary Diagnosis results and treatment plan intent to ensure consistency of tumour site.
 - **Used to derive**
 - Grouped histology codes (hn1_SNOMED_group)
 - **Descriptives:**
-

6b Histology: text description*hn1_na6b_cb_histology_desc*

- **Data check**
 - Text fields were used to complete missing values for Histology codes.
 - **Used to derive**
 - Grouped histology codes (hn1_SNOMED_group)
 - **Descriptives:**
-

Notes: – These variables have not been documented in this data manual. However, they have been cleaned to ensure a consistent coding scheme and were used to derive other variables (see ‘Used to derive’ above). The data for these unprocessed variables are available on request.

8 Gender*hn1_na8_cb_sex*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 4: Gender

BL - Sex:- 1=Male, 2=Female	No.	Col %	Cum %
1 - Male	3908	72.8	72.8
2 - Female	1461	27.2	100.0
Total	5369	100.0	

Notes:

9 Ethnicity

hn1_na9_cb_ethnicity

- Data check
- Used to derive
- Descriptives:

Table 5: Ethnicity

BL - Ethnicity:	No.	Col %	Cum %
1 - A1 - White British	4908	91.4	91.4
2 - B1 - White Irish	44	0.8	92.2
3 - C1 - Other White	84	1.6	93.8
4 - D1 Mixed - White + Black Caribb.	4	0.1	93.9
6 - F1 - Mixed - White + Asian	1	0.0	93.9
7 - G1 - Other Mixed	9	0.2	94.1
8 - H1 - Asian-Indian or British Indian	47	0.9	94.9
9 - J1 - Asian-Pakistani or British Pakistani.	22	0.4	95.3
10 - K1 - Asian-Bangl. or British Bangl.	2	0.0	95.4
11 - L1 - Any other Asian	18	0.3	95.7
12 - M1 - Black/British Caribb.	13	0.2	96.0
13 - N1 - Black-African/British African	14	0.3	96.2
14 - P1 - Other Black	6	0.1	96.3
15 - R1 - Chinese	8	0.1	96.5
16 - S1 - Other ethnic group	23	0.4	96.9
17 - Z1 - Not stated/given	153	2.8	99.8
18 - Z2 - Patient refused	6	0.1	99.9
.a - Missing	7	0.1	100.0
Total	5369	100.0	

Notes:

3.1.2 Section B - Treatment

1 Cancer plan intent

hn1_nbl_cb_plan_intent_1

- Data check
- Used to derive
- Descriptives:

Table 6: Baseline - Cancer plan intent

BL - Plan Intent 1:	No.	Col %	Cum %
1 - Curative	5211	97.1	97.1
2 - Palliative	142	2.6	99.7
3 - Supportive	15	0.3	100.0
.a - Missing	1	0.0	100.0
Total	5369	100.0	

Notes:

2 Planned cancer treatment type

hn1_nb2a_cb_surg_primary,
hn1_nb2b_cb_surg_neck,
hn1_nb2c_cb_telether,
hn1_nb2d_cb_chemother,
hn1_nb2e_cb_hormone,
hn1_nb2f_cb_specialist,
hn1_nb2g_cb_brachyther,
hn1_nb2h_cb_biological,
hn1_nb2i_cb_other,
hn1_nb2j_cb_monitoring,
hn1_nb2k_cb_chemradther,
hn1_nb2l_cb_reconstruct,
hn1_nb2m_cb_laser_surg

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 7: Baseline - Planned cancer treatment type

	No.
BL - Surgery(Primary Site):	
1 - Yes	2449
BL - Surgery(Neck):	
1 - Yes	1410
BL - Teletherapy:	
1 - Yes	1625
BL - Chemotherapy:	
1 - Yes	599
BL - Hormone therapy:	
1 - Yes	7
BL - Specialist Paliative:	
1 - Yes	14
BL - Brachytherapy:	
1 - Yes	131
BL - Biological:	
1 - Yes	67
BL - Other:	
1 - Yes	102
BL - Active Monitoring:	
1 - Yes	146
BL - Combined chemoradiotherapy:	
1 - Yes	1711
BL - Reconstruction with free flap:	
1 - Yes	582
BL - Laser surgery:	
1 - Yes	108

Notes:

3 Treatment type sequence*hn1_nb3_cb_sequence*

- **Data check**
- **Used to derive**
- **Descriptives:**

Notes: – Data for this field are currently undergoing further processing. A cleaned version of this variable will be available in a future data release.

4 Co-morbidity*hn1_nb4_cb_comorb_index*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 8: Baseline - Co-morbidity

BL - Co-morb index:	No.	Col %	Cum %
1 - No co-morbidity	2285	42.6	42.6
2 - Mild discompensation	1768	32.9	75.5
3 - Moderate discompensation	946	17.6	93.1
4 - Severe discompensation	254	4.7	97.8
5 - Unknown	115	2.1	100.0
.a - Missing	1	0.0	100.0
Total	5369	100.0	

Notes:

5 TNM Category

- **Data check**
- **Used to derive**
 - Final pre-treatment staging - (hn1_TNM_stage)
- **Descriptives:**

Table 9: Baseline - T, N & M codes

hn1_nb5b_cb_t_New	No.	Col %	Cum %
1	1249	23.3	23.3
1a	175	3.3	26.5
1b	109	2.0	28.6
2	1744	32.5	61.0
2a	6	0.1	61.1
2b	14	0.3	61.4
3	771	14.4	75.8
4	657	12.2	88.0
4a	404	7.5	95.5
4b	74	1.4	96.9
x	155	2.9	99.8
	11	0.2	100.0
Total	5369	100.0	

hn1_nb5c_cb_n_New	No.	Col %	Cum %
0	2746	51.1	51.1
1	586	10.9	62.1
2	1949	36.3	98.4
3	79	1.5	99.8
x	1	0.0	99.9
	8	0.1	100.0
Total	5369	100.0	

hn1_nb5d_cb_m_New	No.	Col %	Cum %
0	5276	98.3	98.3
1	63	1.2	99.4
x	2	0.0	99.5
	28	0.5	100.0
Total	5369	100.0	

Notes:

6 Side of tumour*hn1_nb6_cb_side_tumor*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 10: Baseline - Side of tumour

BL - Side of primary tumor:	No.	Col %	Cum %
1 - Left	2268	42.2	42.2
2 - Right	2384	44.4	86.6
3 - Midline	328	6.1	92.8
4 - Bilateral	164	3.1	95.8
5 - Left/Midline	25	0.5	96.3
6 - Right/Midline	39	0.7	97.0
.a - Missing	161	3.0	100.0
Total	5369	100.0	

Notes:

7 Side of neck disease*hn1_nb7_cb_side_disease*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 11: Baseline - Side of neck disease

BL - Side of neck disease:	No.	Col %	Cum %
1 - Left	1052	19.6	19.6
2 - Right	1119	20.8	40.4
3 - Midline	20	0.4	40.8
4 - Bilateral	401	7.5	48.3
5 - NA	2746	51.1	99.4
.a - Missing	31	0.6	100.0
Total	5369	100.0	

Notes:

8 Is this tumour the first primary?*hn1_nb8a_cb_first*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 12: Baseline - Is this tumour the first primary?

BL - Is this tumor:	No.	Col %	Cum %
1 - The first HN primary	5244	97.7	97.7
2 - Patient had a previous HN primary	103	1.9	99.6
.a - Missing	22	0.4	100.0
Total	5369	100.0	

Notes:

9a Tumour HPV status using: p16*hn1_nb9a_cb_hpv_status*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 13: Baseline - p16 HPV status

BL - Is this tumor:	No.	Col %	Cum %
1 - Positive	1118	20.8	20.8
2 - Negative	444	8.3	29.1
3 - Not obtained	3790	70.6	99.7
4 - Unequivocal	10	0.2	99.9
.a - Missing	7	0.1	100.0
Total	5369	100.0	

Notes:

9b Tumour HPV status using: DNA by ISH*hn1_nb9b_cb_ish*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 14: Baseline - HPV DNA by ISH

BL - HPV STATUS:	No.	Col %	Cum %
1 - Positive	183	3.4	3.4
2 - Negative	91	1.7	5.1
3 - Not obtained	5088	94.8	99.9
.a - Missing	7	0.1	100.0
Total	5369	100.0	

Notes:

9c Tumour HPV status using: DNA by PCR*hn1_nb9c_cb_pcr*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 15: Baseline - HPV DNA by PCR

BL - HPV DNA by PCR:	No.	Col %	Cum %
2 - Negative	23	0.4	0.4
3 - Not obtained	5336	99.4	99.8
.a - Missing	10	0.2	100.0
Total	5369	100.0	

Notes:

3.1.3 Section C - Other

1 Patient trial status

*hn1_ncl_cb_pts_trial_status***Table 16:** Baseline - Patient trial status

BL - Patient trial status:	No.	Col %	Cum %
1 - Eligible, entered	997	18.6	18.6
2 - Eligible, declined	120	2.2	20.8
3 - Eligible, not approached	244	4.5	25.3
4 - Ineligible	899	16.7	42.1
5 - Not applicable	3078	57.3	99.4
.a - Missing	31	0.6	100.0
Total	5369	100.0	

Notes:

2 Comments*hn1_nc2_cb_comments*

Notes: • This is a free text field and will not be documented. Data for this variable are available through a standard data request.

3.1.4 Derived variables

Variables derived from the Baseline Data Capture Forms.

1. Age at date of consent to nearest year

hn1_dv_age

- **Definition**

- Date of Consent (*hn1_na1_cb_date*) - Date of Birth (*hn1_na2_cb_dob*)
- Stata code to derive variable:

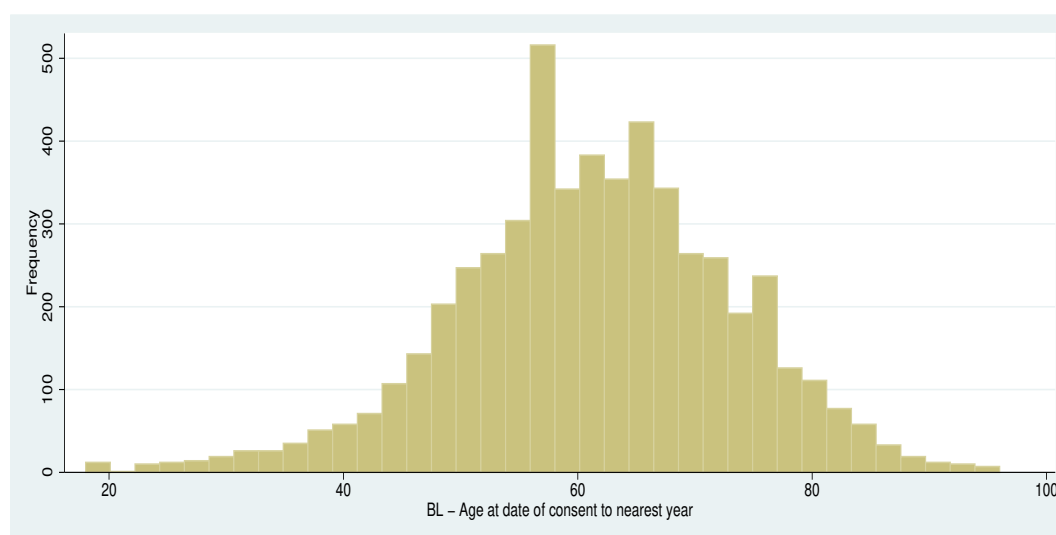
$$* \text{ gen hn1_dv_age}=(\text{hn1_na1_cb_date}-\text{hn1_na2_cb_dob})/365.25$$

- **Used to derive**

- **Descriptives:**

- Total valid responses = 5369, number of missing values or data check errors = 0

Figure 2: Age at date of consent to nearest year



Notes:

2. Days from consent to referral

hn1_dv_ref_age

- **Definition**

- Date of referral (*hn1_na3_cb_dor*) - Date of Birth (*hn1_na2_cb_dob*)
- Stata code to derive variable:

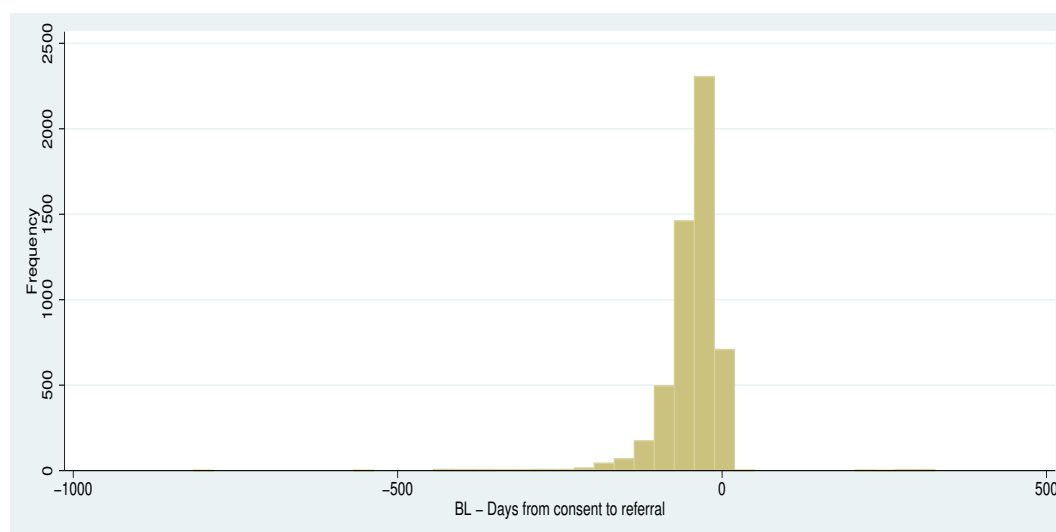
```
* gen hn1_dv_ref_age=hn1_na3_cb_dor-hn1_na2_cb_dob
```

- **Used to derive**

- **Descriptives:**

- Total valid responses = 5324, number of missing values or data check errors = 45

Figure 3: Days from consent to referral



Notes:

- Please use caution when analysing time intervals between the following events: age at referral, age at diagnosis and age at MDT treatment decision. These events may not be in the expected chronological order.

3. Days from consent to date of diagnosis

hn1_dv_diag_age

- **Definition**

- Date of diagnosis (*hn1_na4_cb_diagn*) - Date of Birth (*hn1_na2_cb_dob*)
- Stata code to derive variable:

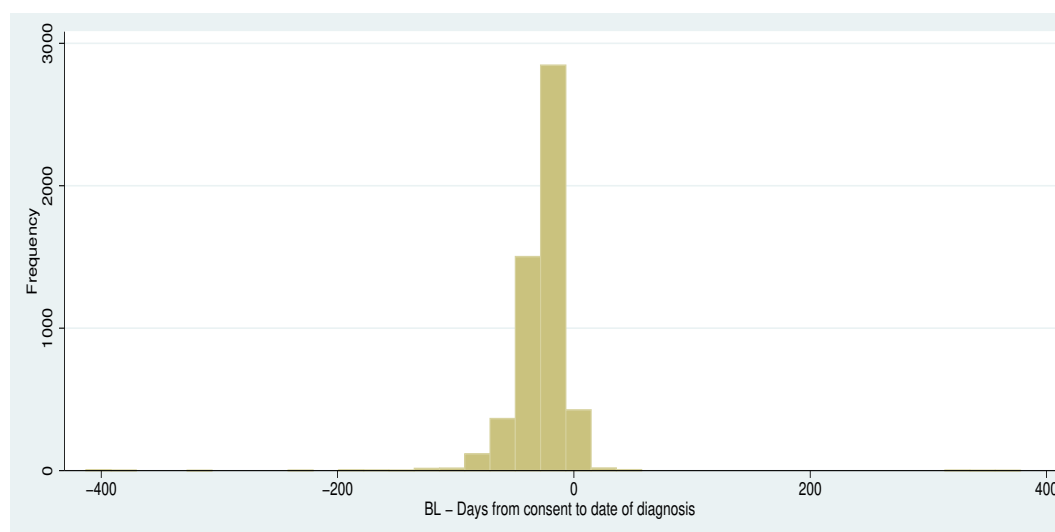
```
* gen hn1_dv_diag_age=hn1_na4_cb_diagn-hn1_na2_cb_dob
```

- **Used to derive**

- **Descriptives:**

- Total valid responses = 5336, number of missing values or data check errors = 33

Figure 4: Days from consent to date of diagnosis



Notes:

- Please use caution when analysing time intervals between the following events: age at referral, age at diagnosis and age at MDT treatment decision. These events may not be in the expected chronological order.

4. Days from consent to MDT decision date

hn1_dv_mdt_age

- **Definition**

- Date of MDT decision (*hn1_na7_cb_mdt_date*) - Date of Birth (*hn1_na2_cb_dob*)
- Stata code to derive variable:

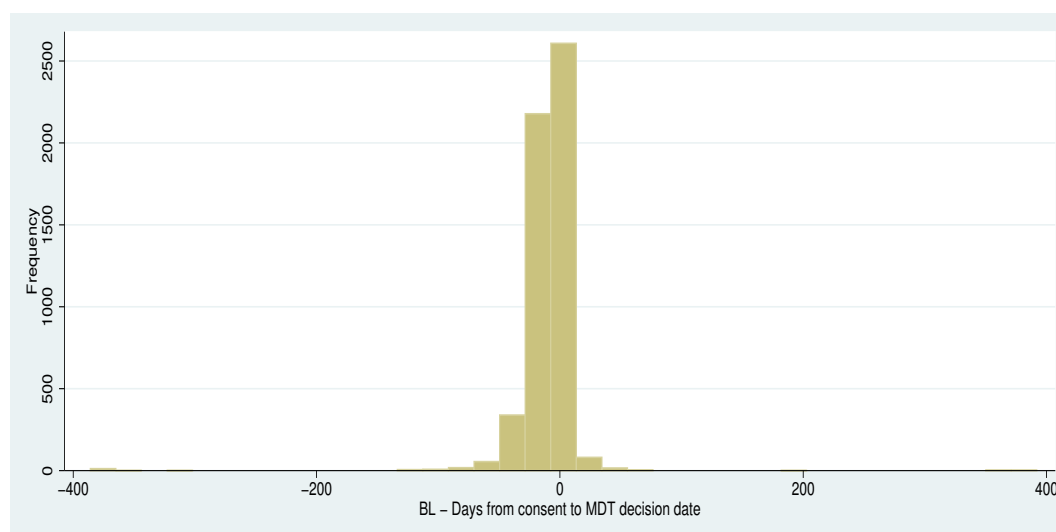
```
* gen hn1_dv_mdt_age=hn1_na7_cb_mdt_date-hn1_na2_cb_dob
```

- **Used to derive**

- **Descriptives:**

- Total valid responses = 5334, number of missing values or data check errors = 35

Figure 5: Days from consent to MDT decision date



Notes:

- Please use caution when analysing time intervals between the following events: age at referral, age at diagnosis and age at MDT treatment decision. These events may not be in the expected chronological order.

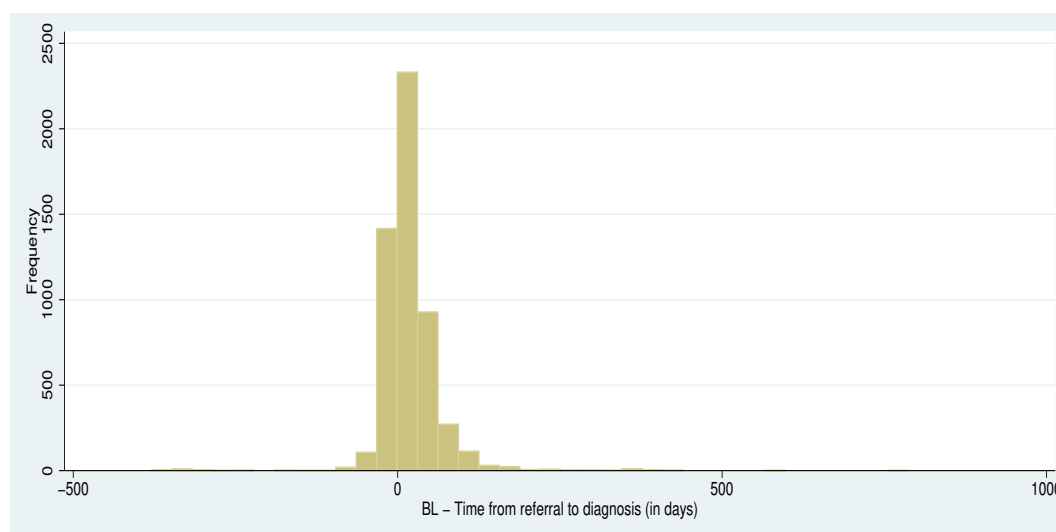
5. Time from referral to diagnosis (in days)

hn1_dv_ref_diag• **Definition**

- Date of Diagnosis (*hn1_na4_cb_diagnosis*) - Date of Referral (*hn1_na3_cb_dor*)
- Stata code to derive variable:
 - * gen hn1_dv_ref_diag = hn1_na4_cb_diagnosis - hn1_na3_cb_dor

• **Used to derive**• **Descriptives:**

- Total valid responses = 5304, number of missing values or data check errors = 65

Figure 6: Time from referral to diagnosis (in days)

Notes: – Negative values for this derived variable are currently being investigated.

6. Time from referral to MDT treatment decision

hn1_dv_ref_mdt

- **Definition**

- Date of MDT treatment decision (*hn1_na7_cb_mdt_date*) - Date of referral (*hn1_na3_cb_dor*)
- Stata code to derive variable:

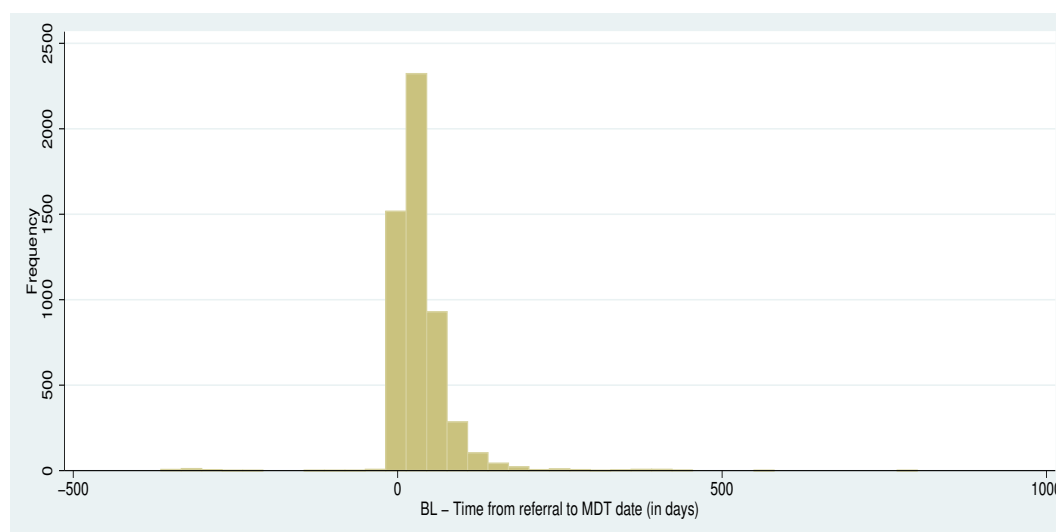
```
* gen hn1_dv_ref_mdt = hn1_na7_cb_mdt_date - hn1_na3_cb_dor
```

- **Used to derive**

- **Descriptives:**

- Total valid responses = 5297, number of missing values or data check errors = 72

Figure 7: Time from referral to MDT date (in days)



Notes: – Negative values for this derived variable are currently being investigated.

7. Location of tumours based on cleaned ICD codes

hn1_ICD_group

ICD codes were grouped as follows:

- 0 - Missing valid ICD code
- 1 - Oral Cavity = C00, C00.0, C00.1, C00.3, C00.4, C00.9, C02.-, C02.0, C02.1, C02.2, C02.3, C02.8, C02.9, C03.0, C03.1, C04.-, C04.0, C04.1, C04.8, C04.9, C05.-, C05.0, C05.2, C05.9, C06.-, C06.0, C06.1, C06.2, C06.8
- 2 - Oropharynx = C01, C02.4, C05.1, C05.8, C09.-, C09.0, C09.1, C09.8, C09.9, C10.-, C10.2, C10.3, C10.8, C10.9
- 3 - Nasopharynx = C11.-, C11.0, C11.1, C11.2, C11.3, C11.8, C11.9
- 4 - Hypopharynx = C10.0, C12, C13, C13.0, C13.1, C13.2, C13.8, C13.9
- 5 - Larynx = C10.1, C32, C32.0, C32.1, C32.2, C32.3, C32.8, C32.9
- 6 - Thyroid = C73
- 7 - Salivary glands = C06.9, C07, C08.-, C08.0, C08.1, C08.9
- 8 - Nasal cavity = C30.-, C30.0
- 9 - Sinuses = C31.-, C31.0, C31.1, C31.2, C31.3, C31.8, C31.9
- 10 - Unknown primary = C76, C76.0, C80.-, C80.0, C80.9

- **Used to derive**

- Final pre-treatment staging - (hn1_TNM_stage)

Table 17: Baseline - Grouped ICD codes

BL - Grouped ICD code	No.	Col %	Cum %
1 - Oral Cavity	1330	24.8	24.8
2 - Oropharynx	1915	35.7	60.4
3 - Nasopharynx	130	2.4	62.9
4 - Hypopharynx	248	4.6	67.5
5 - Larynx	1078	20.1	87.6
6 - Thyroid	261	4.9	92.4
7 - Salivary Glands	136	2.5	95.0
8 - Nasal cavity	58	1.1	96.0
9 - Sinuses	60	1.1	97.2
10 - Unknown Primary	153	2.8	100.0
Total	5369	100.0	

Notes: • Records marked 'Clinical code ungrouped' are currently awaiting further clarification of the primary site using pathology data.

8. Grouping of cleaned histology codes

hn1_SNOMED_group

SNOMED codes were grouped as follows:

- 1 - M8070/3 = "Squamous carcinoma (Not otherwise specified)"
- 2 - M8071/3 = "Keratinising squamous carcinoma"
- 3 - M8072/3 = "Non-keratinising squamous carcinoma"
- 4 - Other SNOMED codes
- .b - Missing - under investigation

Table 18: Baseline - Grouped SNOMED codes

BL - Grouped SNOMED code	No.	Col %	Cum %
1 - Squamous carcinoma (Not otherwise specified)	4089	76.2	76.2
2 - Keratinising squamous carcinoma	339	6.3	82.5
3 - Non-keratinising squamous carcinoma	176	3.3	85.8
4 - Other	758	14.1	99.9
.b - Missing - under investigation	7	0.1	100.0
Total	5369	100.0	

- Notes:**
- The pathology records of those patients with SNOMED codes currently marked as 'Missing - under investigation' are being reviewed by the Head & Neck pathologist.

9. Final clinical pre-treatment staging

hn1_TNM_stage

Using pre-treatment TNM categories

Table 19: Baseline - Final clinical pre-treatment staging

BL - TNM staging	No.	Col %	Cum %
1 - I	1180	22.0	22.0
2 - II	864	16.1	38.1
3 - IIa	12	0.2	38.3
4 - IIb	19	0.4	38.6
5 - III	689	12.8	51.5
6 - IVa	2217	41.3	92.8
7 - IVb	123	2.3	95.1
8 - IVc	55	1.0	96.1
.e - Incomplete T and/or N and/or M codes	30	0.6	96.6
.f - TNM combination unacceptable	27	0.5	97.2
.g - Other	153	2.8	100.0
Total	5369	100.0	

- Notes:**
- Tumour staging was derived using the 'TNM staging of head and neck cancer and neck dissection classification' Deschler and Day (2008).
 - The 'Other' category refers to patients with either an unknown primary tumour site, no valid ICD code or with a valid ICD code which is not currently allocated to a tumour site group. Refer to *hn1_ICD_group* for more details.

10. Simplified - Final clinical pre-treatment staging

hn1_TNM_stage2

Using pre-treatment TNM categories

Table 20: Baseline - Simplified - Final clinical pre-treatment staging

BL - Simplified TNM staging	No.	Col %	Cum %
1 - I	1186	22.1	22.1
2 - II	899	16.7	38.8
3 - III	711	13.2	52.1
4 - IV	2406	44.8	96.9
.e - Incomplete T and/or N and/or M codes	10	0.2	97.1
.f - TNM combination unacceptable	4	0.1	97.2
.g - Other	153	2.8	100.0
Total	5369	100.0	

- Notes:**
- The simplified tumour staging was derived using a modified version of the ‘TNM staging of head and neck cancer and neck dissection classification’ Deschler and Day (2008). See Appendix B for details.
 - The ‘Other’ category refers to patients with either an unknown primary tumour site, no valid ICD code or with a valid ICD code which is not currently allocated to a tumour site group. Refer to *hn1_ICD_group* for more details.

11. IMD quintiles using 2010 national cut-points

hn1_IMD10quint

Derived from participants' home postcode and using the 2010 UK Index of Multiple Deprivation

Table 21: Baseline - IMD quintiles using 2010 national cut-points

BL - IMD quintiles using 2010 national cut-points	No.	Col %	Cum %
0 - Least deprived	899	16.7	16.7
1 - Less	886	16.5	33.2
2 - Middle	1030	19.2	52.4
3 - More	894	16.7	69.1
4 - Most deprived	978	18.2	87.3
.a - Missing	682	12.7	100.0
Total	5369	100.0	

- Notes:**
- The underlying IMD scores and ranks may be available on special request.
 - If you would like to use raw postcode data please contact the HN5000 study team to discuss whether this may be possible.
 - At present IMD quintiles have been derived for people living in England and Wales only. Future data releases may incorporate the Scottish IMD.

3.2 Questionnaires

3.2.1 About You

The topics covered in the 'About You' questionnaire are:

1. Education and occupation - (Lagiou et al., 2009)
2. Income - (Benzeval et al., 2009)
3. EQ5D - (Brooks et al., 2003)
4. Smoking and alcohol - (The Million Women Study Collaborative Group, 1999; Sitas et al., 2013)

Further details of the questionnaire used can be found in Appendix B.2.1 on page 467.

In order to protect the confidentiality of participants the following date variables are not available. Variables have been derived (see the appropriate ‘Derived variables’ sections) which describe participants’ age at events. These variables can be used to define timelines for participants.

A1 Date of completion (*hn1_a1_ay_date*) - Please use ‘Age at completion of baseline AY (days)’ (*hn1_dv_ay_age*)

A2 Date of birth (*hn1_a2_ay_dob*) - Please use ‘Age at baseline (in years)’ (*hn1_dv_age*)

A3a Self-reported height (cm)*hn1_a3a_ay_cms_height***A3b Self-reported height (feet)***hn1_a3b_ay_feet_height***A3c Self-reported height (inches)***hn1_a3c_ay_inches_height*

Notes: • These variables have not been documented. Please refer to the derived variable which combines these variables in a single variable for 'height' - *hn1_dv_height_m*.

A4a Self-reported weight (kg)*hn1_a4a_ay_kg_weight***A4b1 Self-reported weight (stone)***hn1_a4b1_ay_stone_weight***A4b2 Self-reported weight (lbs)***hn1_a4b2_ay_lbs_weight*

Notes: • These variables have not been documented. Please refer to the derived variable which combines these variables in a single variable for ‘weight’ - *hn1_dv_weight_kg*.

A5 Marital status*hn1_a5_ay_marital_status*

- **Data check**
- **Used to derive**
- **Descriptives:**

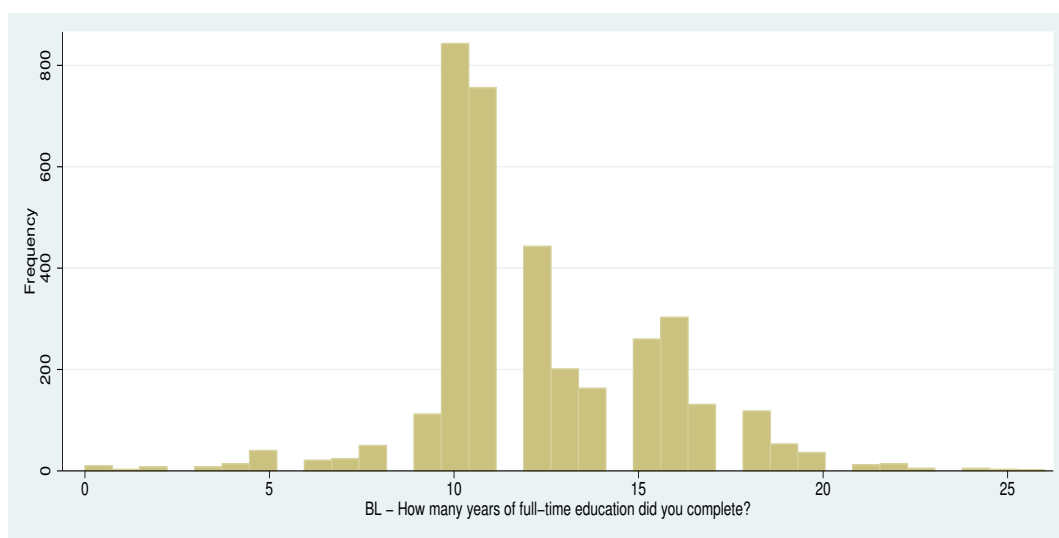
Table 22: Baseline - AY: Marital status

BL - Are you currently:	No.	Col %	Cum %
1 - Single	487	12.1	12.1
2 - Widowed	277	6.9	19.0
3 - Separated	88	2.2	21.2
4 - Married	2265	56.4	77.6
5 - Divorced	410	10.2	87.8
6 - Living with a partner	437	10.9	98.6
.a - Missing	55	1.4	100.0
Total	4019	100.0	

Notes:

A6 How many years of full-time education did you complete?*hn1_a6_ay_education_years*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 3638, number of missing values or data check errors = 381

Figure 8: Baseline - AY: How many years of full-time education did you complete?**Notes:**

A7 What is the highest educational level you obtained?*hn1_a7a_ay_education_level*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 23: Baseline - AY: What is the highest educational level you obtained?

BL - What is the highest educational level you obtained:	No.	Col %	Cum %
1 - Primary School	60	1.5	1.5
2 - Secondary School	1714	42.6	44.1
3 - School or college sixth form	316	7.9	52.0
4 - College FE	672	16.7	68.7
5 - Uni or Poly	710	17.7	86.4
6 - Other college	312	7.8	94.2
.a - Missing	235	5.8	100.0
Total	4019	100.0	

Notes:

A8 Are you a current/former/never user of tobacco?*hn1_a8_ay_tobacco*

- **Data check**
- **Used to derive**
- **Descriptives:**

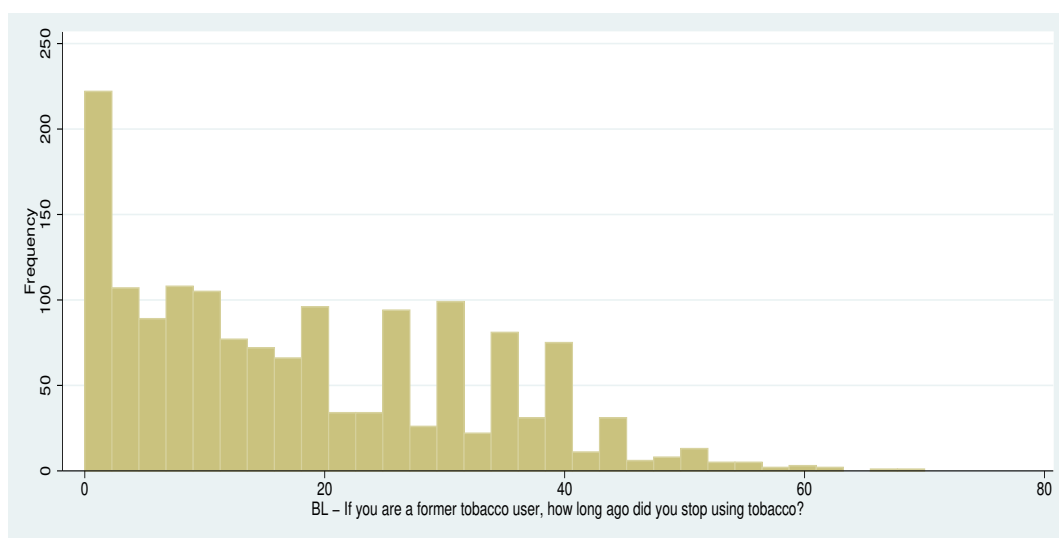
Table 24: Baseline - AY: Are you a current/former/never user of tobacco?

BL - Tobacco	No.	Col %	Cum %
1 - Current user	739	18.4	18.4
2 - Former	2129	53.0	71.4
3 - Never	936	23.3	94.7
.a - Missing	215	5.3	100.0
Total	4019	100.0	

Notes:

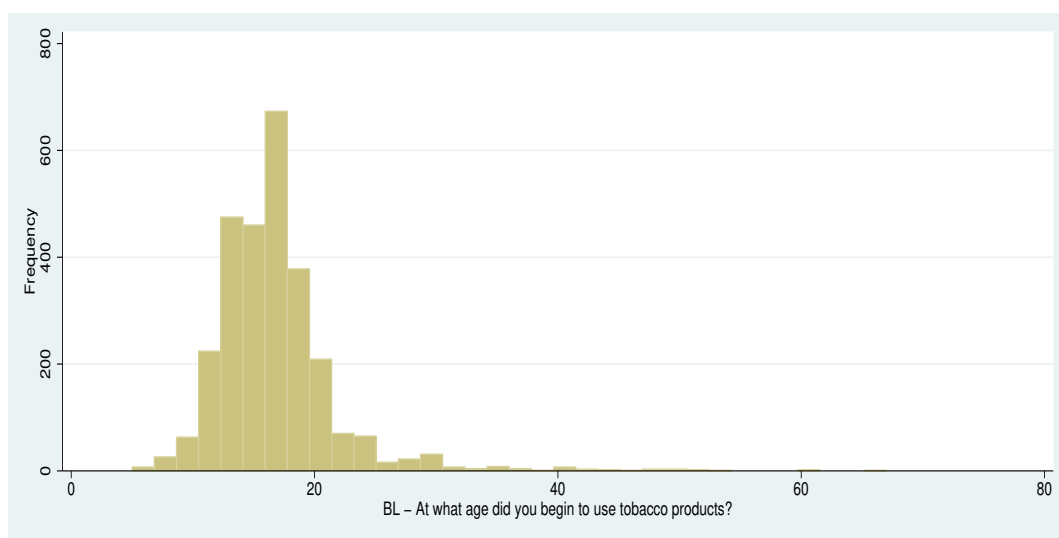
A9 If you are a former tobacco user, how long ago did you stop using tobacco?*hn1_a9_ay_former_tobac_user*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 1526, number of missing values or data check errors = 603

Figure 9: Baseline - AY: If you are a former tobacco user, how long ago did you stop using tobacco?**Notes:**

A10 At what age did you begin to use tobacco products?*hn1_a10_ay_begin_tobac_use*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 2768, number of missing values or data check errors = 100

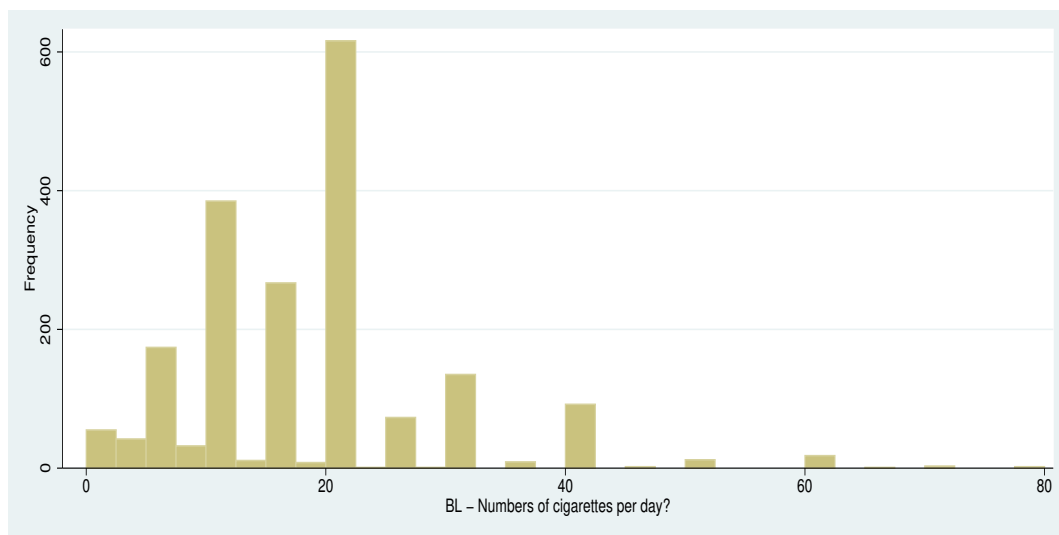
Figure 10: Baseline - AY: At what age did you begin to use tobacco products?**Notes:**

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

a) Numbers of cigarettes per day? - *hn1_alla_ay_cigs_pd*

– Total valid responses = 1939, number of missing values or data check errors = 929

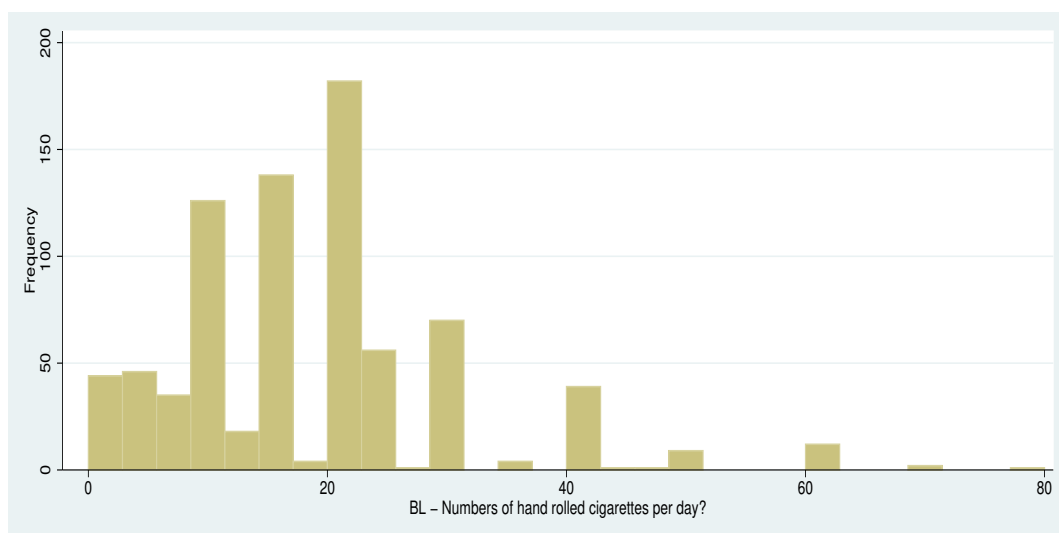
Figure 11: Baseline - AY: Number of cigarettes per day?



b) Numbers of hand rolled cigarettes per day? - *hn1_allb_ay_hand_pd*

– Total valid responses = 789, number of missing values or data check errors = 2079

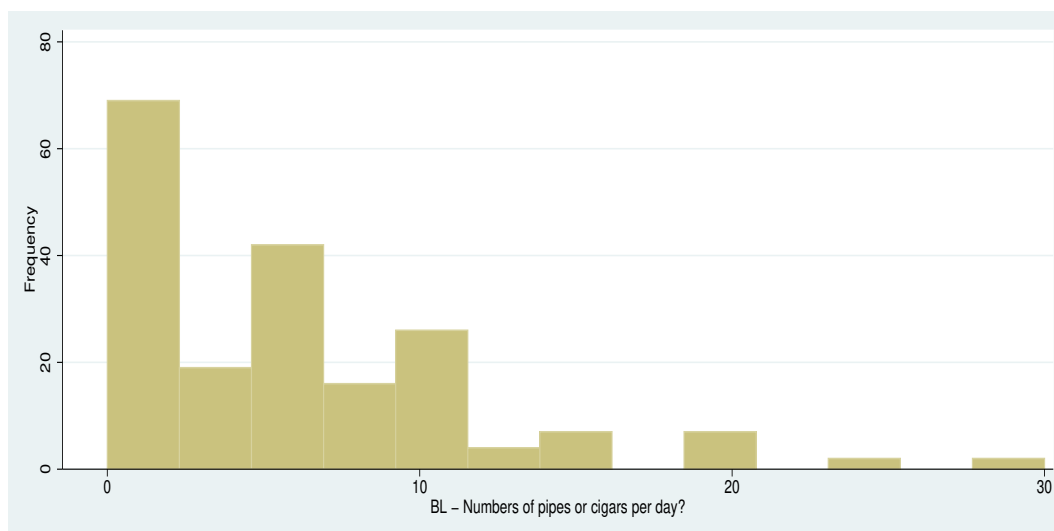
Figure 12: Baseline - AY: Number of hand rolled cigarettes per day?



c) Numbers of pipes or cigars per day? - *hn1_allc_ay_pipe_pd*

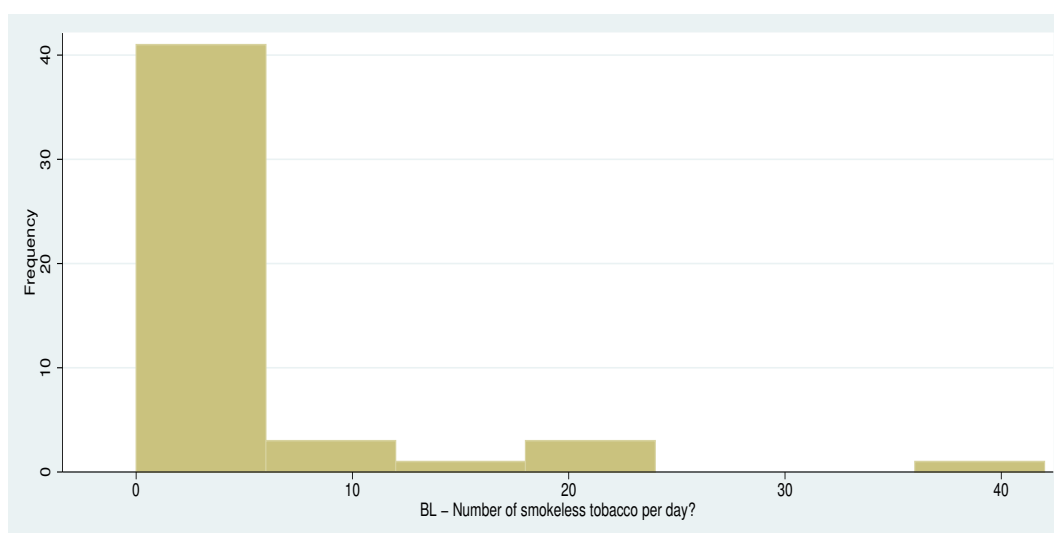
– Total valid responses = 194, number of missing values or data check errors = 2674

Figure 13: Baseline - AY: Number of pipes or cigars per day?

d) Numbers of smokeless tobacco per day? - *hn1_alld_ay_smokeless_pd*

– Total valid responses = 49, number of missing values or data check errors = 2819

Figure 14: Baseline - AY: Number of smokeless tobacco per day?



Notes:

A12 What brand of cigarettes/tobacco do you/did you normally smoke?*hn1_a12_ay_brand_smoke*

Notes: • This is a free text field and will not be documented. Data for this variable are available through a standard data request.

A13a In a typical week how many days do you drink alcohol?*hn1_a13a_ay_drink_days*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 25: Baseline - AY: In a typical week how many days do you drink alcohol?

BL - In a typical week how many days do you drink alcohol?	No.	Col %	Cum %
0	180	4.5	4.5
1	450	11.2	15.7
2	474	11.8	27.5
3	385	9.6	37.0
4	284	7.1	44.1
5	298	7.4	51.5
6	129	3.2	54.7
7	695	17.3	72.0
.a	1124	28.0	100.0
Total	4019	100.0	

A13b 'None' ticked - *hn1_a13b_ay_drink_days***Table 26:** Baseline - AY: None ticked

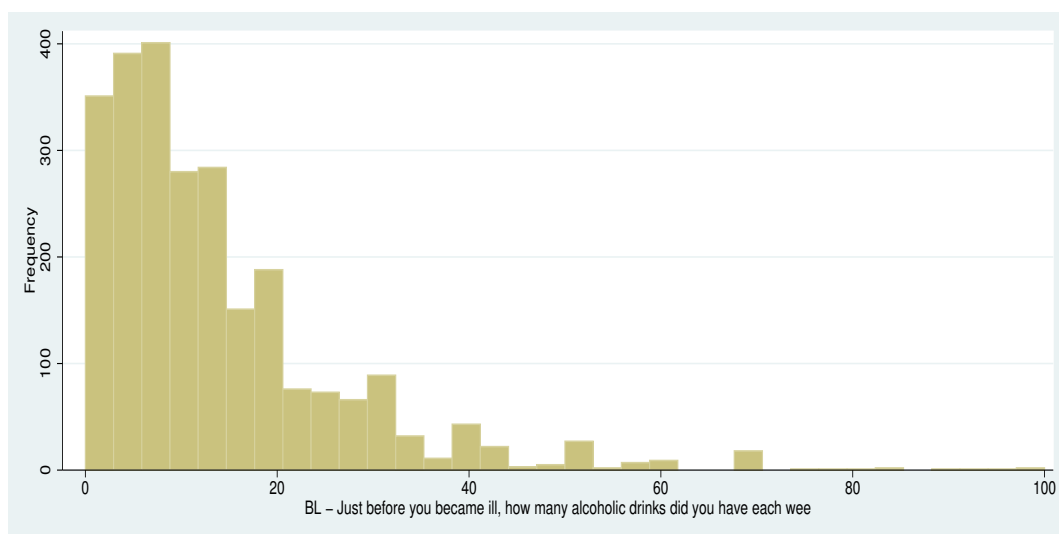
BL - If none, tick the box and go to question A17	No.	Col %	Cum %
1 - Ticked	1010	25.1	25.1
.a - Missing	3009	74.9	100.0
Total	4019	100.0	

Notes:

A14 Just before you became ill, how many alcoholic drinks did you have each week?*hn1_a14_ay_before_ill*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 2539, number of missing values or data check errors = 470

Figure 15: Baseline - AY: Just before you became ill, how many alcoholic drinks did you have each week?



Notes:

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

Table 27: Baseline - AY: About how many bottles of wine, spirits and pints of beers did you drink on average each week?

a) Bottles of wine - *hn1_a15a_ay_wine_pw*

BL - About how many bottles of wine,did you drink on average each week?	No.	Col %	Cum %
1 - None	575	19.1	19.1
2 - Less than 1	472	15.7	34.8
3 - 1	331	11.0	45.8
4 - 2-3	407	13.5	59.3
5 - 4-6	143	4.8	64.1
6 - 7-10	45	1.5	65.6
7 - 11 or more	14	0.5	66.0
.a - Missing	1022	34.0	100.0
Total	3009	100.0	

b) Bottles of Spirits - *hn1_a15b_ay_spirits_pw*

BL - About how many bottles of spirits,did you drink on average each week?	No.	Col %	Cum %
1 - None	901	29.9	29.9
2 - Less than 1	403	13.4	43.3
3 - 1	123	4.1	47.4
4 - 2-3	64	2.1	49.6
5 - 4-6	12	0.4	50.0
6 - 7-10	4	0.1	50.1
7 - 11 or more	2	0.1	50.1
.a - Missing	1500	49.9	100.0
Total	3009	100.0	

c) Pints of beer/lager/cider - *hn1_a15c_ay_pints_pw*

BL - About how many pints of beers, did you drink on average each week?	No.	Col %	Cum %
1 - None	414	13.8	13.8
2 - Less than 7	828	27.5	41.3
3 - 7-14	483	16.1	57.3
4 - 15-21	241	8.0	65.3
5 - 22-28	109	3.6	69.0
6 - 28-35	102	3.4	72.3
7 - 36 or more	107	3.6	75.9
.a - Missing	725	24.1	100.0
Total	3009	100.0	

Notes:

A16 What brand of alcohol do you/did you normally drink?*hn1_a16_ay_brand*

Notes: • This is a free text field and will not be documented. Data for this variable are available through a standard data request.

A17 Are you currently working?*hn1_a17_ay_working*

- **Data check**
- **Used to derive**
- **Descriptives:**

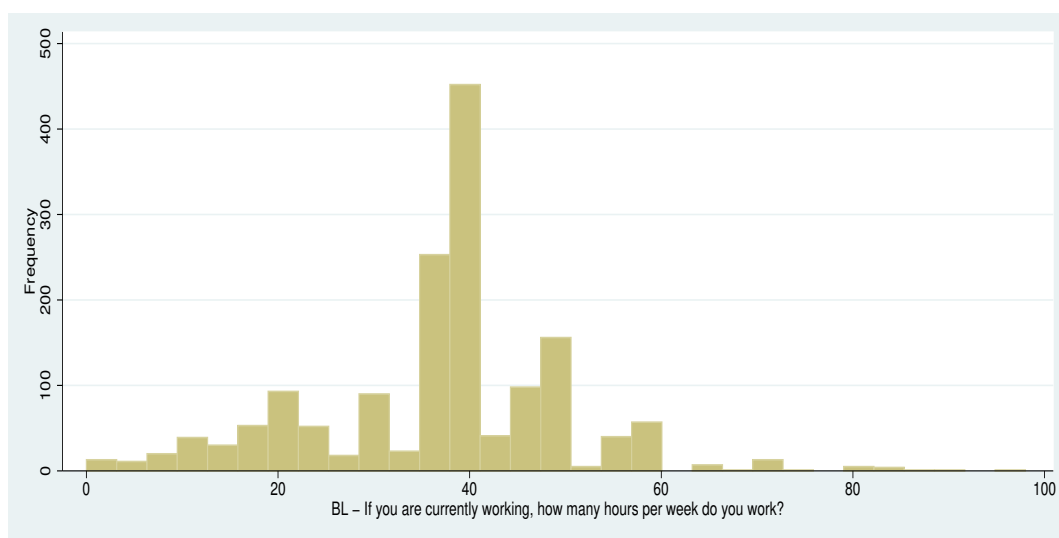
Table 28: Baseline - AY: Are you currently working?

BL - Are you currently working:	No.	Col %	Cum %
1 - Yes	1557	38.7	38.7
2 - No	2399	59.7	98.4
.a - Missing	63	1.6	100.0
Total	4019	100.0	

Notes:

A18 If you are currently working, how many hours per week do you work?*hn1_a18_ay_now_work_hours*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 1578, number of missing values or data check errors = 2441

Figure 16: Baseline - AY: If you are currently working, how many hours per week do you work?**Notes:**

A19 What was the occupation/job which you had for the longest time in your life?*hn1_a19_ay_occup_longest*

Notes: • This is a free text field and will not be documented. Data for this variable are available through a standard data request.

A20 Have you ever been unemployed?*hn1_a20_ay_employed*

- Data check
- Used to derive
- Descriptives:

Table 29: Baseline - AY: Have you ever been unemployed?

BL - Have you ever been unemployed:	No.	Col %	Cum %
1 - Yes	1831	45.6	45.6
2 - No	2002	49.8	95.4
.a - Missing	186	4.6	100.0
Total	4019	100.0	

Notes:

A21 What is your total household income from all sources before tax and other deductions?*hn1_a21_ay_hhold_income*

- **Data check**
- **Used to derive**
 - *hn1_dv_a21_ay_hhold_income*
- **Descriptives:**

Table 30: Baseline - AY: What is your total household income from all sources before tax and other deductions?

BL - What is your total household income	No.	Col %	Cum %
1 - Less than £77	85	2.1	2.1
2 - £77-154	225	5.6	7.7
3 - £155-£230	188	4.7	12.4
4 - £231-£346	136	3.4	15.8
5 - £347-£442	57	1.4	17.2
6 - £443-£558	45	1.1	18.3
7 - £559-£673	20	0.5	18.8
8 - £674 or more	26	0.6	19.5
9 - Less than £3999	83	2.1	21.5
10 - £4000-£7999	164	4.1	25.6
11 - £8000-£11999	267	6.6	32.2
12 - £12000-£17999	417	10.4	42.6
13 - £18000-£22999	276	6.9	49.5
14 - £23000-£28999	357	8.9	58.4
15 - £29000-34999	274	6.8	65.2
16 - £35000 or more	810	20.2	85.3
.a - Missing	589	14.7	100.0
Total	4019	100.0	

Notes:

- The derived variable *hn1_dv_a21_ay_hhold_income*, which combines the responses to ‘weekly’ and ‘annual’ income into a consistent scale should be used instead of this variable.

A22 What proportion of your household income (including your own) would you say comes from benefits?*hn1_a22_ay_hhold_inc_benefit*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 31: Baseline - AY: What proportion of your household income (including your own) would you say comes from benefits?

BL - What proportion of your household income:	No.	Col %	Cum %
1 - None	2497	62.1	62.1
2 - About a quarter	163	4.1	66.2
3 - About three quarters	89	2.2	68.4
4 - Very little	352	8.8	77.2
5 - About half	118	2.9	80.1
6 - All	553	13.8	93.9
.a - Missing	247	6.1	100.0
Total	4019	100.0	

Notes:

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

Table 32: Baseline - AY: At present do you have any concerns about any of the following aspects of living with or after cancer?

- None - *hn1_a23a_ay_lc_none*

BL - Aspects of living with or after cancer: None	No.	Col %	Cum %
1 - Yes	1837	45.7	45.7
2 - No	1942	48.3	94.0
.a - Missing	240	6.0	100.0
Total	4019	100.0	

- Financial concerns - *hn1_a23b_ay_lc_financial*

BL - Aspects of living with or after cancer: Financial concerns	No.	Col %	Cum %
1 - Yes	1379	34.3	34.3
2 - No	2399	59.7	94.0
.a - Missing	241	6.0	100.0
Total	4019	100.0	

- Staying in college/work - *hn1_a23c_ay_lc_stay_work*

BL - Aspects of living with or after cancer: Staying in work/college	No.	Col %	Cum %
1 - Yes	425	10.6	10.6
2 - No	3352	83.4	94.0
.a - Missing	242	6.0	100.0
Total	4019	100.0	

- Cost of attending appointments - *hn1_a23d_ay_lc_cost*

BL - Aspects of living with or after cancer: Cost of attending appointments	No.	Col %	Cum %
1 - Yes	936	23.3	23.3
2 - No	2841	70.7	94.0
.a - Missing	242	6.0	100.0
Total	4019	100.0	

- Taking time off work/college - *hn1_a23e_ay_lc_time_off*

BL - Aspects of living with or after cancer: Taking time off work/college	No.	Col %	Cum %
1 - Yes	722	18.0	18.0
2 - No	3055	76.0	94.0
.a - Missing	242	6.0	100.0
Total	4019	100.0	

- Returning to work/college - *hn1_a23f_ay_lc_return_work*

BL - Aspects of living with or after cancer: Returning to work/college	No.	Col %	Cum %
1 - Yes	523	13.0	13.0
2 - No	3255	81.0	94.0
.a - Missing	241	6.0	100.0
Total	4019	100.0	

A24 Please tick the box that describes best what you can do:*hn1_a24_ay_what_you_do*

- Data check
- Used to derive
- Descriptives:

Table 33: Baseline - AY: Please tick the box that describes best what you can do:

BL - Please tick the box that describes best what you can do	No.	Col %	Cum %
1 - Able to carry out all normal activities without restriction	2141	53.3	53.3
2 - Restricted in physically strenuous activity but able to walk and do light work	989	24.6	77.9
3 - Able to walk and all self care but unable to carry out any work up and about more than 50% of waking hours	523	13.0	90.9
4 - Capable of only limited self care confined to bed or chair more than 50% of waking hours	161	4.0	94.9
.a - Missing	22	0.5	95.4
Total	183	4.6	100.0

Notes:

A25 Please indicate which statements best describes your own health state today**Table 34:** Baseline - AY: Please indicate which statements best describes your own health state todaya) Mobility - *hn1_a25a_ay_hlth_mobility*

BL - Mobility	No.	Col %	Cum %
1 - I have no problems walking about	2775	69.0	69.0
2 - I have slight problems walking about	219	5.4	74.5
3 - I have moderate problems walking about	821	20.4	94.9
4 - I have severe problems walking about	89	2.2	97.1
5 - I am unable to walk about	12	0.3	97.4
.a - Missing	103	2.6	100.0
Total	4019	100.0	

b) Self care - *hn1_a25b_ay_hlth_self_care*

BL - Self care	No.	Col %	Cum %
1 - I have no prob washing or dressing myself	3481	86.6	86.6
2 - I have slight prob washing or dressing myself	96	2.4	89.0
3 - I have moderat prob washing or dressing myself	291	7.2	96.2
4 - I have svr prob washing or dressing myself	14	0.3	96.6
5 - I am unable to wash or dress myself	24	0.6	97.2
.a - Missing	113	2.8	100.0
Total	4019	100.0	

c) Usual activities - *hn1_a25c_ay_hlth_usual_activ*

BL - Usual activities	No.	Col %	Cum %
1 - I have no prob with doing usual activities	2599	64.7	64.7
2 - I have slight probs with doing usual activities	284	7.1	71.7
3 - I have mod probs doing usual activities	850	21.1	92.9
4 - I have sevr probs doing usual activities	48	1.2	94.1
5 - I am unable to do usual actvts	114	2.8	96.9
.a - Missing	124	3.1	100.0
Total	4019	100.0	

d) Pain discomfort - *hn1_a25d_ay_hlth_pain*

BL - Pain discomfort	No.	Col %	Cum %
1 - I have no pain or discomfort	1383	34.4	34.4
2 - I have slight pain or discomfort	558	13.9	48.3
3 - I have moderate pain or discomfort	1631	40.6	88.9
4 - I have severe pain or discomfort	126	3.1	92.0
5 - I have extreme pain of discomfort	220	5.5	97.5
.a - Missing	101	2.5	100.0
Total	4019	100.0	

e) Anxiety/depression - *hn1_a25e_ay_hlth_anxiety*

BL - Anxiety/depression	No.	Col %	Cum %
1 - I am not anxious or depressed	1816	45.2	45.2
2 - I am slightly anxious or depressed	531	13.2	58.4
3 - I am moderately anxious or depressed	1333	33.2	91.6
4 - I am severely anxious or depressed	57	1.4	93.0
5 - I am extremely anxious or depressed	127	3.2	96.1
.a - Missing	155	3.9	100.0
Total	4019	100.0	

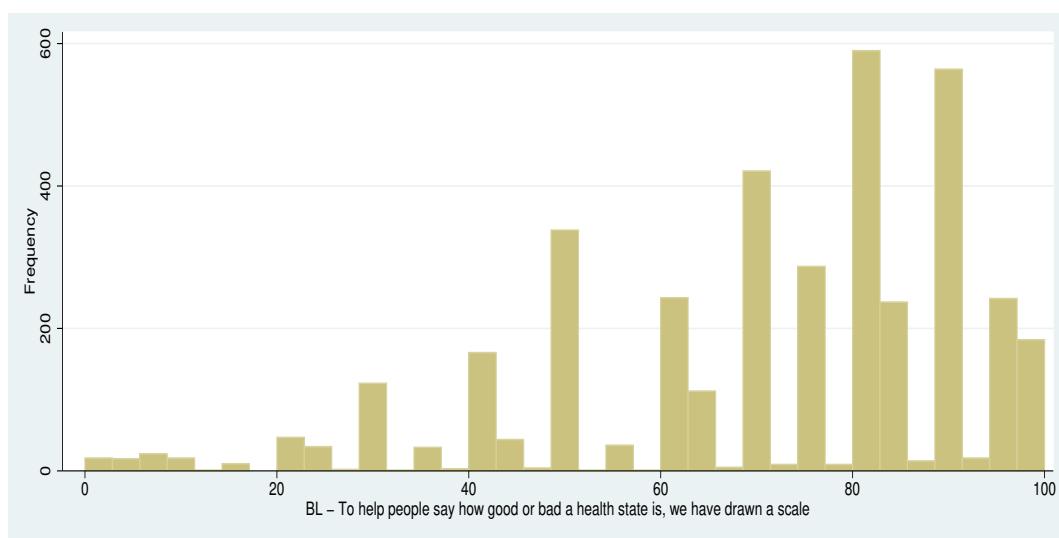
• EQ5D questionnaire version - *hn1_eq5d_version*

BL - EQ5D questionnaire version	No.	Col %	Cum %
1 - EQ5D-3L	1628	40.5	40.5
2 - EQ5D-5L	2340	58.2	98.7
.a - Missing	51	1.3	100.0
Total	4019	100.0	

Notes: • Early versions of the Baseline - About You questionnaire used the EQ5D-3L, rather than EQ5D-5L. EQ5D-3L results have been mapped onto the EQ5D-5L scale as 1=1, 2=3 and 3=5. The EQ5D questionnaire version is included in the variable *hn1_eq5d_version*.

A26 Please describe how good or bad your health state is today*hn1_a26_ay_hlth_state_scale*

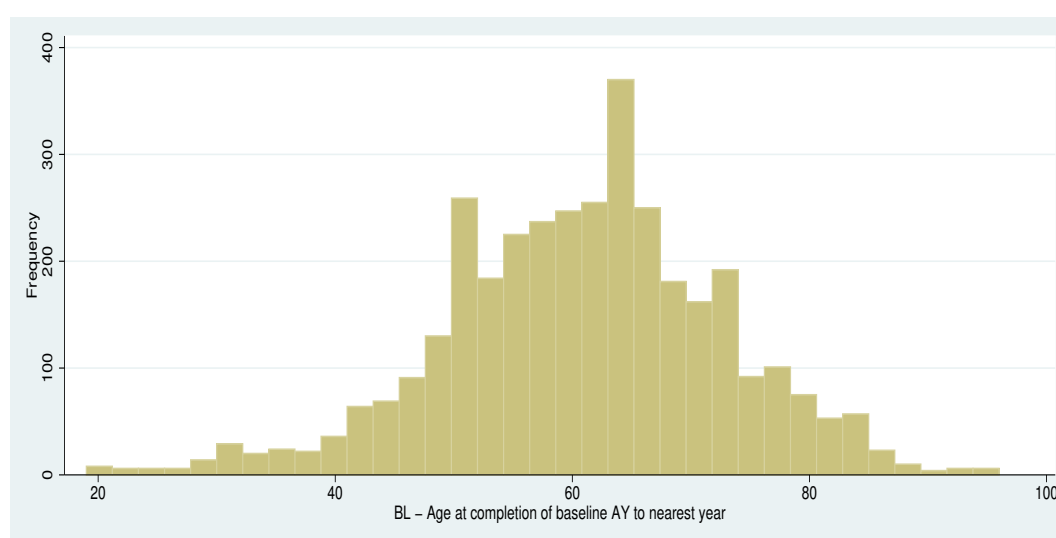
- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 3856, number of missing values or data check errors = 163

Figure 17: Baseline - AY: Please describe how good or bad your health state is today**Notes:**

3.2.2 About You - Derived Variables

A1 comp Age at completion of baseline AY (days)*hn1_dv_ay_age*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 3514, number of missing values or data check errors = 505

Figure 18: Baseline - AY: Age at completion of baseline AY (days)**Notes:**

A3 comp Composite variable - height (metres)*hn1_dv_height_m*

- **Data check**

- replace hn1_dv_height_m=. if hn1_dv_height_m>2.3 | hn1_dv_height_m<0.7

- **Used to derive**

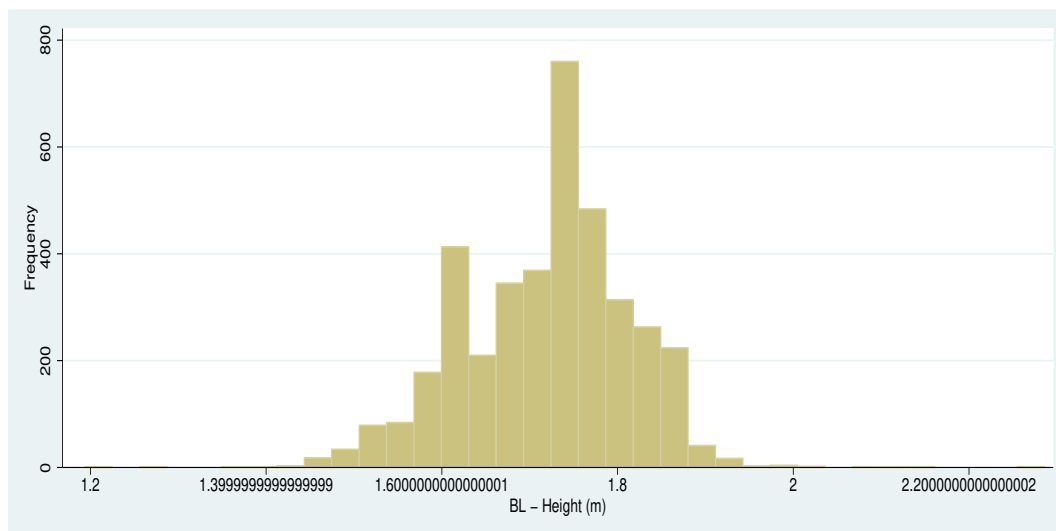
- *hn1_dv_BMI*

- Stata code to derive variable:

- gen hn1_dv_height_m = .
- replace hn1_dv_height_m = hn1_a3a_ay_cms_height/100 if hn1_a3a_ay_cms_height < .
- replace hn1_dv_height_m=(hn1_a3b_ay_feet_height * 0.3048) if hn1_a3b_ay_feet_height < .
- replace hn1_dv_height_m=hn1_dv_height_m+(hn1_a3c_ay_inches_height * 0.0254) if hn1_a3c_ay_inches_height < . & hn1_dv_height_m < .

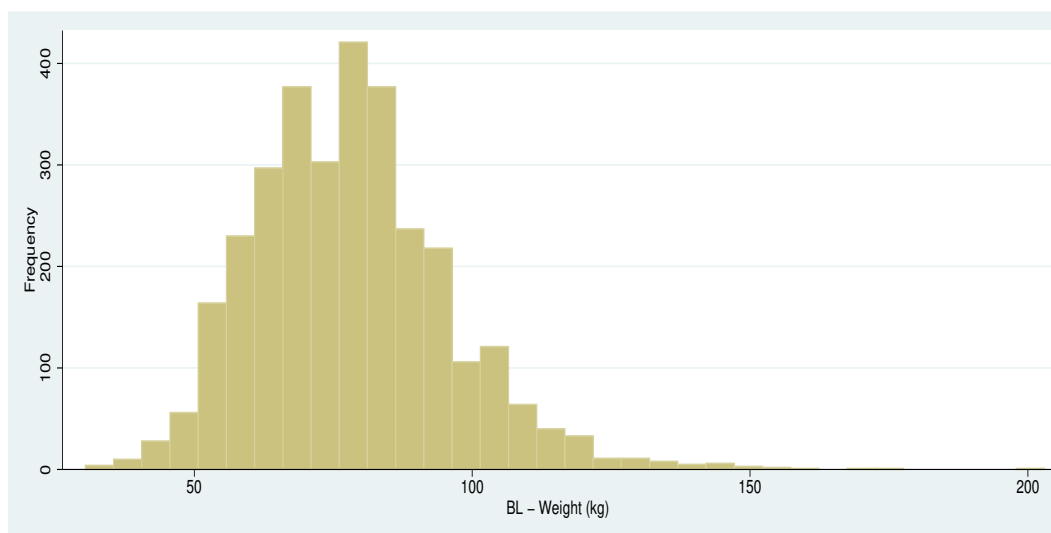
- **Descriptives:**

- Total valid responses = 3853, number of missing values or data check errors = 166

Figure 19: Baseline - AY: Composite variable - height (metres)**Notes:**

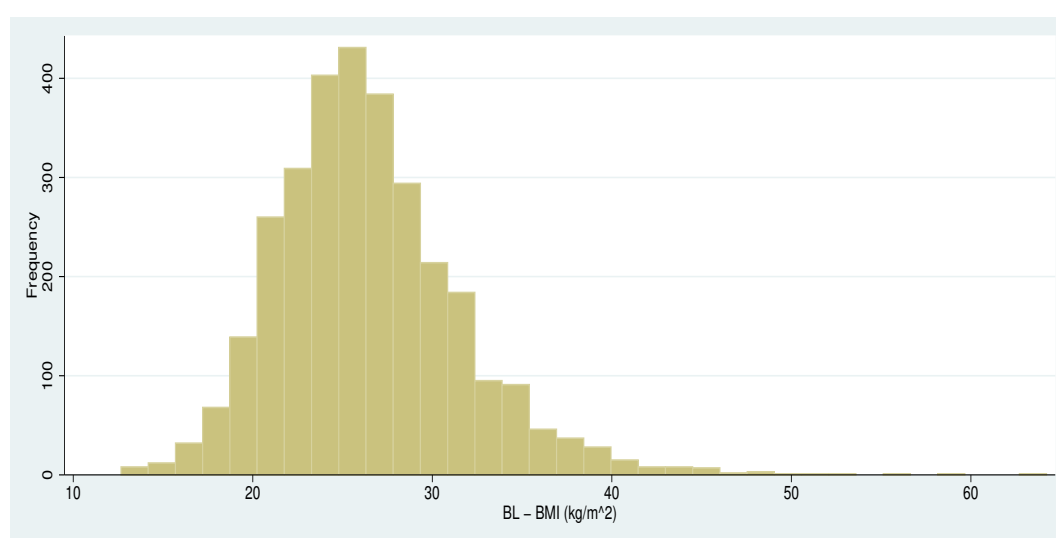
A4 comp Composite variable - weight (kg)*hn1_dv_weight_kg*

- **Data check**
 - replace hn1_dv_weight_kg=. if hn1_dv_weight_kg<20
- **Used to derive**
 - *hn1_dv_BMI*
- **Stata code to derive variable:**
 - gen hn1_dv_weight_kg = .
 - replace hn1_dv_weight_kg = hn1_a4_a_ay_kg_weight
 - replace hn1_dv_weight_kg = (hn1_a4_b1_ay_stone_weight * 6.35029) if hn1_a4_b1_ay_stone_weight<.
 - replace hn1_dv_weight_kg = (hn1_a4_b1_ay_stone_weight * 6.35029) + (hn1_a4_b2_ay_lbs_weight * 0.453592) if hn1_a4_b1_ay_stone_weight<.& hn1_a4_b2_ay_lbs_weight<.
- **Descriptives:**
 - Total valid responses = 3136, number of missing values or data check errors = 883

Figure 20: Baseline - AY: Composite variable - weight (kg)**Notes:**

A3-4 comp Composite variable - BMI (kg/m²)*hn1_dv_BMI*

- **Stata code to derive variable:**
 - `gen hn1_dv_BMI = hn1_dv_weight_kg/(hn1_dv_height_m^2)`
 - **Descriptives:**
 - Total valid responses = 3084, number of missing values or data check errors = 935
-

Figure 21: Baseline - AY: Composite variable - BMI (kg/m²)**Notes:**

A13-comp1 Are you a current consumer of alcohol?*hn1_dv_drink_ever*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

Table 35: Baseline - AY: Are you a current consumer of alcohol?

BL - Current alcohol consumer	No.	Col %	Cum %
0 - No/never	1076	26.8	26.8
1 - Yes	2715	67.6	94.3
.a - Missing	228	5.7	100.0
Total	4019	100.0	

Notes:

A13-comp2 How many days per week do you drink alcohol?*hn1_dv_drink_days*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

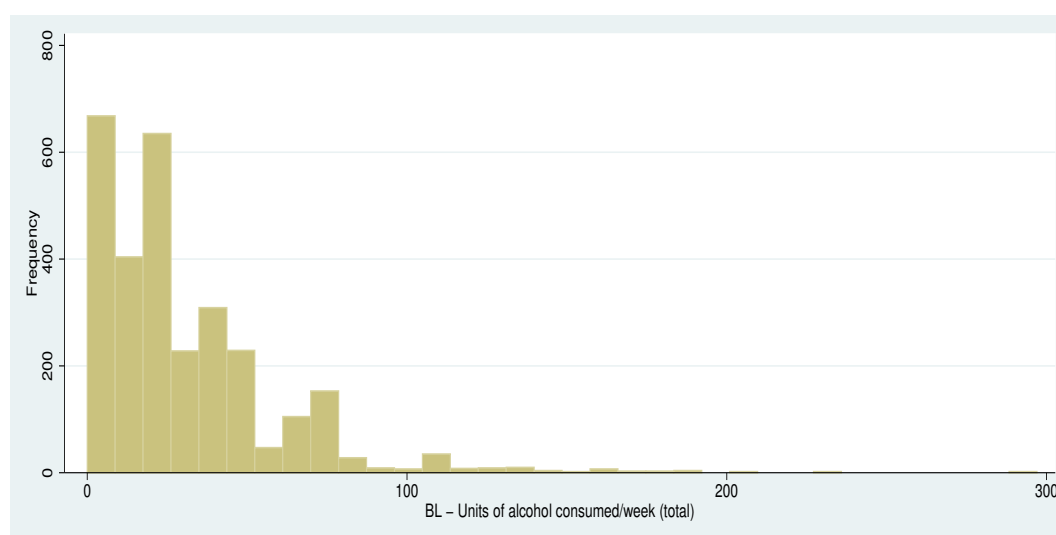
Table 36: Baseline - AY: How many days per week do you drink alcohol?

BL - Days per week alcohol consumed	No.	Col %	Cum %
0 - 0	1076	26.8	26.8
1 - 1	450	11.2	38.0
2 - 2	474	11.8	49.8
3 - 3	385	9.6	59.3
4 - 4	284	7.1	66.4
5 - 5	298	7.4	73.8
6 - 6	129	3.2	77.0
7 - 7	695	17.3	94.3
.a - Missing	228	5.7	100.0
Total	4019	100.0	

Notes:

A13-comp3 What is your total weekly alcohol consumption (units)?*hn1_dv_total_wk*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**
 - Total valid responses = 2913, number of missing values or data check errors = 1106

Figure 22: What is your total weekly alcohol consumption (units)?**Notes:**

A21-comp What is your total annual household income from all sources before tax and other deductions?

hn1_dv_a21_ay_hhold_income

- **Stata code to derive variable:**

- `gen hn1_dv_a21_ay_hhold_income = .`
- `replace hn1_dv_a21_ay_hhold_income=1 if hn1_a21_ay_hhold_income==1 | hn1_a21_ay_hhold_income==9`
- `replace hn1_dv_a21_ay_hhold_income=2 if hn1_a21_ay_hhold_income==2 | hn1_a21_ay_hhold_income==10`
- `replace hn1_dv_a21_ay_hhold_income=3 if hn1_a21_ay_hhold_income==3 | hn1_a21_ay_hhold_income==11`
- `replace hn1_dv_a21_ay_hhold_income=4 if hn1_a21_ay_hhold_income==4 | hn1_a21_ay_hhold_income==12`
- `replace hn1_dv_a21_ay_hhold_income=5 if hn1_a21_ay_hhold_income==5 | hn1_a21_ay_hhold_income==13`
- `replace hn1_dv_a21_ay_hhold_income=6 if hn1_a21_ay_hhold_income==6 | hn1_a21_ay_hhold_income==14`
- `replace hn1_dv_a21_ay_hhold_income=7 if hn1_a21_ay_hhold_income==7 | hn1_a21_ay_hhold_income==15`
- `replace hn1_dv_a21_ay_hhold_income=8 if hn1_a21_ay_hhold_income==8 | hn1_a21_ay_hhold_income==16`

- **Data check:**

- **Used to derive:**

- **Descriptives:**

Table 37: Baseline - AY: Grouped - What is your total annual household income from all sources before tax and other deductions?

BL - Total annual household income	No.	Col %	Cum %
1 - Less than £3999	168	4.2	4.2
2 - £4000-£7999	389	9.7	13.9
3 - £8000-£11999	455	11.3	25.2
4 - £12000-£17999	553	13.8	38.9
5 - £18000-£22999	333	8.3	47.2
6 - £23000-£28999	402	10.0	57.2
7 - £29000-£34999	294	7.3	64.5
8 - £35000+	836	20.8	85.3
.a - Missing	589	14.7	100.0
Total	4019	100.0	

Notes:

3.2.3 Your Outlook

The topics covered in the ‘Your Outlook’ questionnaire are based on the ‘Revised Life Orientation Test (LOT-R)’ (Scheier et al., 1994). Further details of the questionnaire used can be found in Appendix B.2.2 on page 475.

B1 In uncertain times, I usually expect the best. - *hn1_b1_yo_uncertain_times*

Table 38: Baseline - LOT-R: In uncertain times, I usually expect the best.

BL - In uncertain times:	No.	Col %	Cum %
1 - Strongly disagree	77	1.9	1.9
2 - Disagree	493	12.2	14.1
3 - Neutral	1067	26.4	40.5
4 - Agree	1847	45.7	86.3
5 - Strongly agree	461	11.4	97.7
.a - Missing	93	2.3	100.0
Total	4038	100.0	

B2 It's easy for me to relax. - *hn1_b2_yo_relax*

Table 39: Baseline - LOT-R: It's easy for me to relax.

BL - It is easy for me to relax:	No.	Col %	Cum %
1 - Strongly disagree	125	3.1	3.1
2 - Disagree	817	20.2	23.3
3 - Neutral	869	21.5	44.8
4 - Agree	1698	42.1	86.9
5 - Strongly agree	363	9.0	95.9
.a - Missing	166	4.1	100.0
Total	4038	100.0	

B3 If something can go wrong for me, it will. - *hn1_b3_yo_go_wrong*

Table 40: Baseline - LOT-R: If something can go wrong for me, it will.

BL - If something can go wrong for me:	No.	Col %	Cum %
1 - Strongly disagree	378	9.4	9.4
2 - Disagree	1362	33.7	43.1
3 - Neutral	1136	28.1	71.2
4 - Agree	876	21.7	92.9
5 - Strongly agree	171	4.2	97.2
.a - Missing	115	2.8	100.0
Total	4038	100.0	

B4 I'm always optimistic about my future - *hn1_b4_yo_optimistic***Table 41:** Baseline - LOT-R: I'm always optimistic about my future

BL - I am always optimistic about my future:	No.	Col %	Cum %
1 - Strongly disagree	63	1.6	1.6
2 - Disagree	442	10.9	12.5
3 - Neutral	906	22.4	34.9
4 - Agree	1977	49.0	83.9
5 - Strongly agree	578	14.3	98.2
.a - Missing	72	1.8	100.0
Total	4038	100.0	

B5 I enjoy my friends a lot. - *hn1_b5_yo_friends***Table 42:** Baseline - LOT-R: I enjoy my friends a lot.

BL - I enjoy my friends a lot:	No.	Col %	Cum %
1 - Strongly disagree	26	0.6	0.6
2 - Disagree	96	2.4	3.0
3 - Neutral	544	13.5	16.5
4 - Agree	2008	49.7	66.2
5 - Strongly agree	1309	32.4	98.6
.a - Missing	55	1.4	100.0
Total	4038	100.0	

B6 It's important for me to keep busy - *hn1_b6_yo_keep_busy***Table 43:** Baseline - LOT-R: It's important for me to keep busy

BL - It is important for me to keep busy:	No.	Col %	Cum %
1 - Strongly disagree	31	0.8	0.8
2 - Disagree	215	5.3	6.1
3 - Neutral	683	16.9	23.0
4 - Agree	1904	47.2	70.2
5 - Strongly agree	1108	27.4	97.6
.a - Missing	97	2.4	100.0
Total	4038	100.0	

B7 I hardly ever expect things to go my way. - *hn1_b7_yo_go_my_way*

Table 44: Baseline - LOT-R: I hardly ever expect things to go my way.

BL - I hardly ever expect things to go my way:	No.	Col %	Cum %
1 - Strongly disagree	491	12.2	12.2
2 - Disagree	1596	39.5	51.7
3 - Neutral	1117	27.7	79.3
4 - Agree	635	15.7	95.1
5 - Strongly agree	134	3.3	98.4
.a - Missing	65	1.6	100.0
Total	4038	100.0	

B8 I don't get upset too easily. - *hn1_b8_yo_upset*

Table 45: Baseline - LOT-R: I don't get upset too easily.

BL - I do not get upset too easily:	No.	Col %	Cum %
1 - Strongly disagree	120	3.0	3.0
2 - Disagree	636	15.8	18.7
3 - Neutral	848	21.0	39.7
4 - Agree	1976	48.9	88.7
5 - Strongly agree	389	9.6	98.3
.a - Missing	69	1.7	100.0
Total	4038	100.0	

B9 I rarely count on good things happening to me. - *hn1_b9_yo_good_things*

Table 46: Baseline - LOT-R: I rarely count on good things happening to me.

BL - I rarely count on good things happening to me:	No.	Col %	Cum %
1 - Strongly disagree	392	9.7	9.7
2 - Disagree	1344	33.3	43.0
3 - Neutral	1215	30.1	73.1
4 - Agree	869	21.5	94.6
5 - Strongly agree	160	4.0	98.6
.a - Missing	58	1.4	100.0
Total	4038	100.0	

B10 Overall, I expect more good things to happen to me than bad. - *hn1_b10_yo_overall*

Table 47: Baseline - LOT-R: Overall, I expect more good things to happen to me than bad.

BL - Overall, I expect more good things to happen to me than bad.:	No.	Col %	Cum %
1 - Strongly disagree	99	2.5	2.5
2 - Disagree	387	9.6	12.0
3 - Neutral	1042	25.8	37.8
4 - Agree	1970	48.8	86.6
5 - Strongly agree	500	12.4	99.0
.a - Missing	40	1.0	100.0
Total	4038	100.0	

Notes:

3.2.4 Your General Health - EORTC QLQ-C30

The topics covered in the ‘Your General Health’ questionnaire are based on the ‘EORTC QLQ-C30’ questionnaire (Aaronson et al., 1993). Further details of the questionnaire used can be found in Appendix B.2.2 on page 475.

C1 Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? - *hn1_c1_ygh_stren_acttrouble*

Table 48: Baseline - QLQ-C30: Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?

BL - Do you have any trouble doing strenuous activities,like carrying a heavy sh	No.	Col %	Cum %
1 - Not at all	2130	52.7	52.7
2 - A little	994	24.6	77.4
3 - Quite a bit	452	11.2	88.6
4 - Very much	430	10.6	99.2
.a - Missing	32	0.8	100.0
Total	4038	100.0	

C2 Do you have any trouble taking a long walk? - *hn1_c2_ygh_long_walktrouble*

Table 49: Baseline - QLQ-C30: Do you have any trouble taking a long walk?

BL - Do you have any trouble taking a long walk?	No.	Col %	Cum %
1 - Not at all	2177	53.9	53.9
2 - A little	833	20.6	74.5
3 - Quite a bit	407	10.1	84.6
4 - Very much	586	14.5	99.1
.a - Missing	35	0.9	100.0
Total	4038	100.0	

C3 Do you have any trouble taking a short walk outside of the house? - *hn1_c3_ygh_short_walktrouble*

Table 50: Baseline - QLQ-C30: Do you have any trouble taking a short walk outside of the house?

BL - Do you have any trouble taking a short walk outside of the house?	No.	Col %	Cum %
1 - Not at all	3203	79.3	79.3
2 - A little	478	11.8	91.2
3 - Quite a bit	207	5.1	96.3
4 - Very much	114	2.8	99.1
.a - Missing	36	0.9	100.0
Total	4038	100.0	

C4 Do you need to stay in bed or a chair during the day? - *hn1_c4_ygh_stay_bed_daytime***Table 51:** Baseline - QLQ-C30: Do you need to stay in bed or a chair during the day?

BL - Do you need to stay in bed or a chair during the day?	No.	Col %	Cum %
1 - Not at all	3005	74.4	74.4
2 - A little	626	15.5	89.9
3 - Quite a bit	268	6.6	96.6
4 - Very much	72	1.8	98.3
.a - Missing	67	1.7	100.0
Total	4038	100.0	

C5 Do you need help with eating, dressing, washing yourself or using the toilet? - *hn1_c5_ygh_help_with_eating***Table 52:** Baseline - QLQ-C30: Do you need help with eating, dressing, washing yourself or using the toilet?

BL - Do you need help with eating, dressing, washing yourself or using the toile	No.	Col %	Cum %
1 - Not at all	3687	91.3	91.3
2 - A little	218	5.4	96.7
3 - Quite a bit	58	1.4	98.1
4 - Very much	33	0.8	99.0
.a - Missing	42	1.0	100.0
Total	4038	100.0	

C6 Were you limited in doing either your work or other daily activities? - *hn1_c6_ygh_limit_daily_activ***Table 53:** Baseline - QLQ-C30: Were you limited in doing either your work or other daily activities?

BL - Were you limited in doing either your work or other daily activities?	No.	Col %	Cum %
1 - Not at all	2259	55.9	55.9
2 - A little	956	23.7	79.6
3 - Quite a bit	465	11.5	91.1
4 - Very much	303	7.5	98.6
.a - Missing	55	1.4	100.0
Total	4038	100.0	

C7 Were you limited in pursuing your hobbies or other leisure time activities? - *hn1_c7_ygh_limit_hobbies*

Table 54: Baseline - QLQ-C30: Were you limited in pursuing your hobbies or other leisure time activities?

BL - Were you limited in pursuing your hobbies or other leisure time activities?	No.	Col %	Cum %
1 - Not at all	2266	56.1	56.1
2 - A little	864	21.4	77.5
3 - Quite a bit	488	12.1	89.6
4 - Very much	357	8.8	98.4
.a - Missing	63	1.6	100.0
Total	4038	100.0	

C8 Were you short of breath? - *hn1_c8_ygh_short_of_breath*

Table 55: Baseline - QLQ-C30: Were you short of breath?

BL - Were you short of breath?	No.	Col %	Cum %
1 - Not at all	2614	64.7	64.7
2 - A little	967	23.9	88.7
3 - Quite a bit	244	6.0	94.7
4 - Very much	153	3.8	98.5
.a - Missing	60	1.5	100.0
Total	4038	100.0	

C9 Have you had pain? - *hn1_c9_ygh_had_pain*

Table 56: Baseline - QLQ-C30: Have you had pain?

BL - Have you had pain?	No.	Col %	Cum %
1 - Not at all	1398	34.6	34.6
2 - A little	1480	36.7	71.3
3 - Quite a bit	715	17.7	89.0
4 - Very much	401	9.9	98.9
.a - Missing	44	1.1	100.0
Total	4038	100.0	

C10 Did you need to rest? - *hn1_c10_ygh_need_to_rest***Table 57:** Baseline - QLQ-C30: Did you need to rest?

BL - Did you need to rest?	No.	Col %	Cum %
1 - Not at all	1511	37.4	37.4
2 - A little	1587	39.3	76.7
3 - Quite a bit	585	14.5	91.2
4 - Very much	301	7.5	98.7
.a - Missing	54	1.3	100.0
Total	4038	100.0	

C11 Have you had trouble sleeping? - *hn1_c11_ygh_sleep_trouble***Table 58:** Baseline - QLQ-C30: Have you had trouble sleeping?

BL - Have you had trouble sleeping?	No.	Col %	Cum %
1 - Not at all	1287	31.9	31.9
2 - A little	1473	36.5	68.4
3 - Quite a bit	729	18.1	86.4
4 - Very much	507	12.6	99.0
.a - Missing	42	1.0	100.0
Total	4038	100.0	

C12 Have you felt weak? - *hn1_c12_ygh_felt_weak***Table 59:** Baseline - QLQ-C30: Have you felt weak?

BL - Have you felt weak?	No.	Col %	Cum %
1 - Not at all	1874	46.4	46.4
2 - A little	1381	34.2	80.6
3 - Quite a bit	456	11.3	91.9
4 - Very much	273	6.8	98.7
.a - Missing	54	1.3	100.0
Total	4038	100.0	

C13 Have you lacked appetite? - *hn1_c13_ygh_lacked_appetite***Table 60:** Baseline - QLQ-C30: Have you lacked appetite?

BL - Have you lacked appetite?	No.	Col %	Cum %
1 - Not at all	2220	55.0	55.0
2 - A little	1023	25.3	80.3
3 - Quite a bit	456	11.3	91.6
4 - Very much	292	7.2	98.8
.a - Missing	47	1.2	100.0
Total	4038	100.0	

C14 Have you felt nauseated? - *hn1_c14_ygh_felt_auseated***Table 61:** Baseline - QLQ-C30: Have you felt nauseated?

BL - Have you felt nauseated?	No.	Col %	Cum %
1 - Not at all	3015	74.7	74.7
2 - A little	753	18.6	93.3
3 - Quite a bit	150	3.7	97.0
4 - Very much	72	1.8	98.8
.a - Missing	48	1.2	100.0
Total	4038	100.0	

C15 Have you vomited? - *hn1_c15_ygh_vomited***Table 62:** Baseline - QLQ-C30: Have you vomited?

BL - Have you vomited?	No.	Col %	Cum %
1 - Not at all	3705	91.8	91.8
2 - A little	225	5.6	97.3
3 - Quite a bit	46	1.1	98.5
4 - Very much	18	0.4	98.9
.a - Missing	44	1.1	100.0
Total	4038	100.0	

C16 Have you been constipated? - *hn1_c16_ygh_constipated***Table 63:** Baseline - QLQ-C30: Have you been constipated?

BL - Have you been constipated?	No.	Col %	Cum %
1 - Not at all	2612	64.7	64.7
2 - A little	875	21.7	86.4
3 - Quite a bit	325	8.0	94.4
4 - Very much	186	4.6	99.0
.a - Missing	40	1.0	100.0
Total	4038	100.0	

C17 Have you had diarrhoea? - *hn1_c17_ygh_diarrhoea***Table 64:** Baseline - QLQ-C30: Have you had diarrhoea?

BL - Have you had diarrhoea?	No.	Col %	Cum %
1 - Not at all	3372	83.5	83.5
2 - A little	501	12.4	95.9
3 - Quite a bit	95	2.4	98.3
4 - Very much	28	0.7	99.0
.a - Missing	42	1.0	100.0
Total	4038	100.0	

C18 Were you tired? - *hn1_c18_ygh_tired***Table 65:** Baseline - QLQ-C30: Were you tired?

BL - Were you tired?	No.	Col %	Cum %
1 - Not at all	988	24.5	24.5
2 - A little	1935	47.9	72.4
3 - Quite a bit	685	17.0	89.4
4 - Very much	365	9.0	98.4
.a - Missing	65	1.6	100.0
Total	4038	100.0	

C19 Did pain interfere with your daily activities? - *hn1_c19_ygh_pain_daily_activ*

Table 66: Baseline - QLQ-C30: Did pain interfere with your daily activities?

BL - Did pain interfere with your daily activities?	No.	Col %	Cum %
1 - Not at all	2337	57.9	57.9
2 - A little	1036	25.7	83.5
3 - Quite a bit	394	9.8	93.3
4 - Very much	240	5.9	99.2
.a - Missing	31	0.8	100.0
Total	4038	100.0	

C20 Have you had difficulty in concentrating on things, like reading a newspaper or watching television? - *hn1_c20_ygh_difficulty_conc*

Table 67: Baseline - QLQ-C30: Have you had difficulty in concentrating on things, like reading a newspaper or watching television?

BL - Have you had difficulty in concentrating on things, like reading a newspaper	No.	Col %	Cum %
1 - Not at all	2374	58.8	58.8
2 - A little	1096	27.1	85.9
3 - Quite a bit	369	9.1	95.1
4 - Very much	166	4.1	99.2
.a - Missing	33	0.8	100.0
Total	4038	100.0	

C21 Did you feel tense? - *hn1_c21_ygh_feel_tense*

Table 68: Baseline - QLQ-C30: Did you feel tense?

BL - Did you feel tense?	No.	Col %	Cum %
1 - Not at all	1336	33.1	33.1
2 - A little	1862	46.1	79.2
3 - Quite a bit	589	14.6	93.8
4 - Very much	216	5.3	99.1
.a - Missing	35	0.9	100.0
Total	4038	100.0	

C22 Did you worry? - *hn1_c22_ygh_worry***Table 69:** Baseline - QLQ-C30: Did you worry?

BL - Did you worry?	No.	Col %	Cum %
1 - Not at all	753	18.6	18.6
2 - A little	2095	51.9	70.5
3 - Quite a bit	780	19.3	89.8
4 - Very much	364	9.0	98.9
.a - Missing	46	1.1	100.0
Total	4038	100.0	

C23 Did you feel irritable? - *hn1_c23_ygh_irritable***Table 70:** Baseline - QLQ-C30: Did you feel irritable?

BL - Did you feel irritable?	No.	Col %	Cum %
1 - Not at all	1650	40.9	40.9
2 - A little	1677	41.5	82.4
3 - Quite a bit	470	11.6	94.0
4 - Very much	206	5.1	99.1
.a - Missing	35	0.9	100.0
Total	4038	100.0	

C24 Did you feel depressed? - *hn1_c24_ygh_depressed***Table 71:** Baseline - QLQ-C30: Did you feel depressed?

BL - Did you feel depressed?	No.	Col %	Cum %
1 - Not at all	2066	51.2	51.2
2 - A little	1371	34.0	85.1
3 - Quite a bit	360	8.9	94.0
4 - Very much	194	4.8	98.8
.a - Missing	47	1.2	100.0
Total	4038	100.0	

C25 Have you had difficulty remembering things? - *hn1_c25_ygh_mem_diff*

Table 72: Baseline - QLQ-C30: Have you had difficulty remembering things?

BL - Have you had difficulty remembering things?	No.	Col %	Cum %
1 - Not at all	2148	53.2	53.2
2 - A little	1375	34.1	87.2
3 - Quite a bit	339	8.4	95.6
4 - Very much	149	3.7	99.3
.a - Missing	27	0.7	100.0
Total	4038	100.0	

C26 Has your physical condition or medical treatment interfered with your family life? - *hn1_c26_ygh_family_life*

Table 73: Baseline - QLQ-C30: Has your physical condition or medical treatment interfered with your family life?

BL - Has your physical condition or medical treatment interfered with your famil	No.	Col %	Cum %
1 - Not at all	2100	52.0	52.0
2 - A little	1228	30.4	82.4
3 - Quite a bit	433	10.7	93.1
4 - Very much	222	5.5	98.6
.a - Missing	55	1.4	100.0
Total	4038	100.0	

C27 Has your physical condition or medical treatment interfered with your social activities? - *hn1_c27_ygh_social_activ*

Table 74: Baseline - QLQ-C30: Has your physical condition or medical treatment interfered with your social activities?

BL - Has your physical condition or medical treatment interfered with your socia	No.	Col %	Cum %
1 - Not at all	1779	44.1	44.1
2 - A little	1312	32.5	76.5
3 - Quite a bit	544	13.5	90.0
4 - Very much	362	9.0	99.0
.a - Missing	41	1.0	100.0
Total	4038	100.0	

C28 Has your physical condition or medical treatment interfered caused you financial difficulties?

- *hn1_c28_ygh_financial_diff*

Table 75: Baseline - QLQ-C30: Has your physical condition or medical treatment interfered caused you financial difficulties?

BL - Has your physical condition or medical treatment caused you financial diffi	No.	Col %	Cum %
1 - Not at all	2416	59.8	59.8
2 - A little	871	21.6	81.4
3 - Quite a bit	377	9.3	90.7
4 - Very much	321	7.9	98.7
.a - Missing	53	1.3	100.0
Total	4038	100.0	

C29 How would you rate your overall health during the past week? - *hn1_c29_ygh_health_past_wk*

Table 76: Baseline - QLQ-C30: How would you rate your overall health during the past week?

BL - How would you rate your overall health during the past week?(on a scale of	No.	Col %	Cum %
1 - Very poor	121	3.0	3.0
2 - 2	157	3.9	6.9
3 - 3	428	10.6	17.5
4 - 4	688	17.0	34.5
5 - 5	1073	26.6	61.1
6 - 6	1152	28.5	89.6
7 - Excellent	384	9.5	99.1
.a - Missing	35	0.9	100.0
Total	4038	100.0	

C30 How would you rate your overall quality of life during the past week? - *hn1_c30_ygh_lifequal_past_wk*

Table 77: Baseline - QLQ-C30: How would you rate your overall quality of life during the past week?

BL - How would you rate your overall quality of life during the past week?	No.	Col %	Cum %
1 - Very poor	106	2.6	2.6
2 - 2	187	4.6	7.3
3 - 3	408	10.1	17.4
4 - 4	648	16.0	33.4
5 - 5	905	22.4	55.8
6 - 6	1188	29.4	85.2
7 - Excellent	562	13.9	99.2
.a - Missing	34	0.8	100.0
Total	4038	100.0	

Notes:

3.2.5 Your General Health - EORTC QLQ-C30 - Derived Variables

C dev1 Functional scale: Physical Functioning

hn1_dv_c30_phys_func

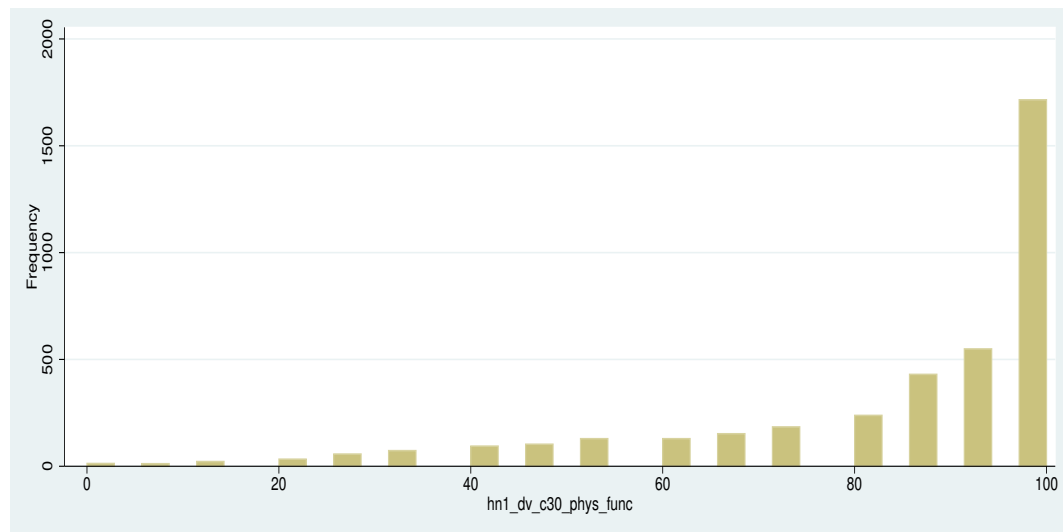
- **Stata code to derive variable:**

- `gen hn1_dv_c30_phys_func = (1-(((hn1_c1_ygh_stren_acttrouble + hn1_c2_ygh_long_walktrouble + hn1_c3_ygh_short_walktrouble + hn1_c4_ygh_stay_bed_daytime + hn1_c5_ygh_help_with_eating-1)/5)-1)/3))*100`

- **Descriptives:**

- Total valid responses = 3933, number of missing values or data check errors = 105

Figure 23: Baseline - QLQ-C30: Functional scale: Physical Functioning



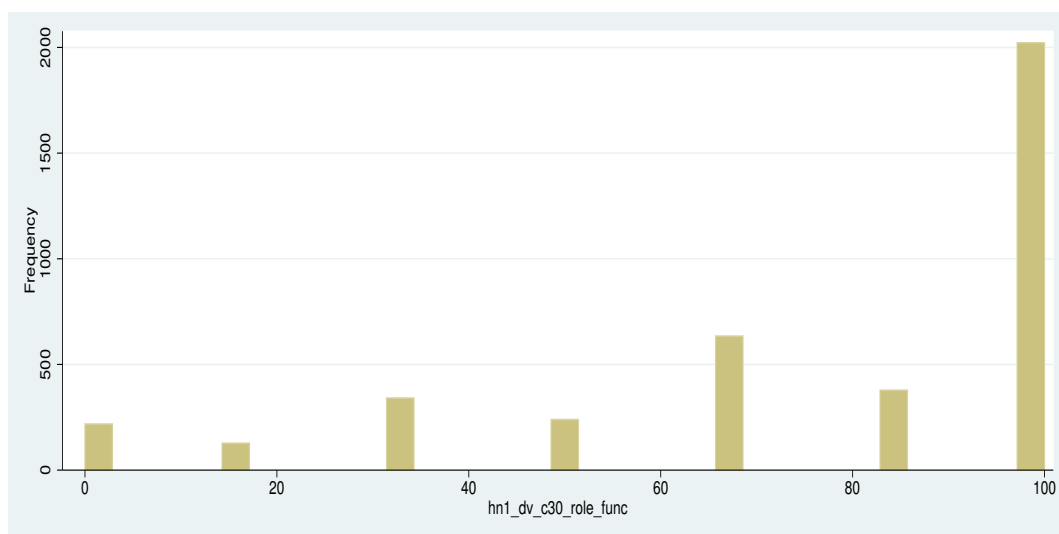
C dev2 Functional scale: Role Functioning*hn1_dv_c30_role_func*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_role_func = (1-(((hn1_c6_ygh_limit_daily_activ + hn1_c7_ygh_limit_hobbies)/2)-1)/3))*100`

- **Descriptives:**

- Total valid responses = 3959, number of missing values or data check errors = 79

Figure 24: Baseline - QLQ-C30: Functional scale: Role Functioning

C dev3 Functional scale: Emotional Functioning

hn1_dv_c30_emot_func

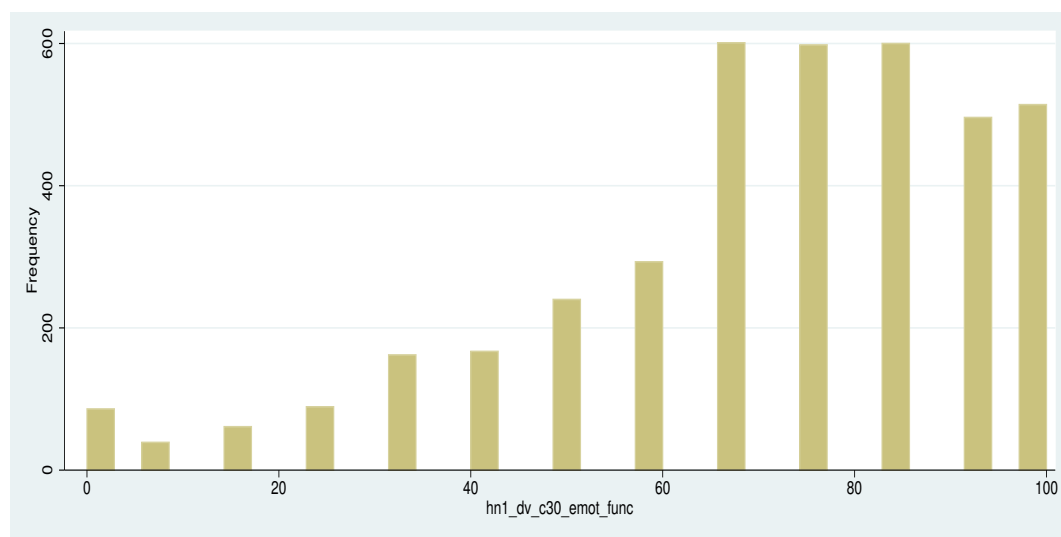
- **Stata code to derive variable:**

- `gen hn1_dv_c30_emot_func = (1-(((hn1_c21_ygh_feel_tense + hn1_c22_ygh_worry + hn1_c23_ygh_irritable + hn1_c24_ygh_depressed)/4)-1)/3))*100`

- **Descriptives:**

- Total valid responses = 3946, number of missing values or data check errors = 92

Figure 25: Baseline - QLQ-C30: Functional scale: Emotional Functioning



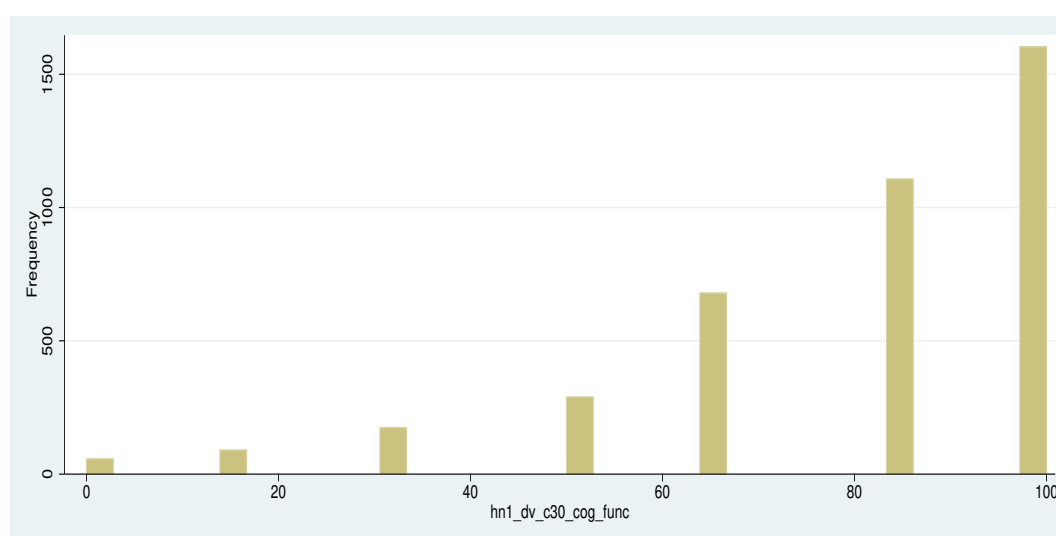
C dev4 Functional scale: Cognitive Functioning*hn1_dv_c30_cog_func*

- **Stata code to derive variable:**

- $\text{gen hn1_dv_c30_cog_func} = (1 - (((\text{hn1_c20_ygh_difficulty_conc} + \text{hn1_c25_ygh_mem_diff})/2) - 1)/3)) * 100$

- **Descriptives:**

- Total valid responses = 3999, number of missing values or data check errors = 39

Figure 26: Baseline - QLQ-C30: Functional scale: Cognitive Functioning

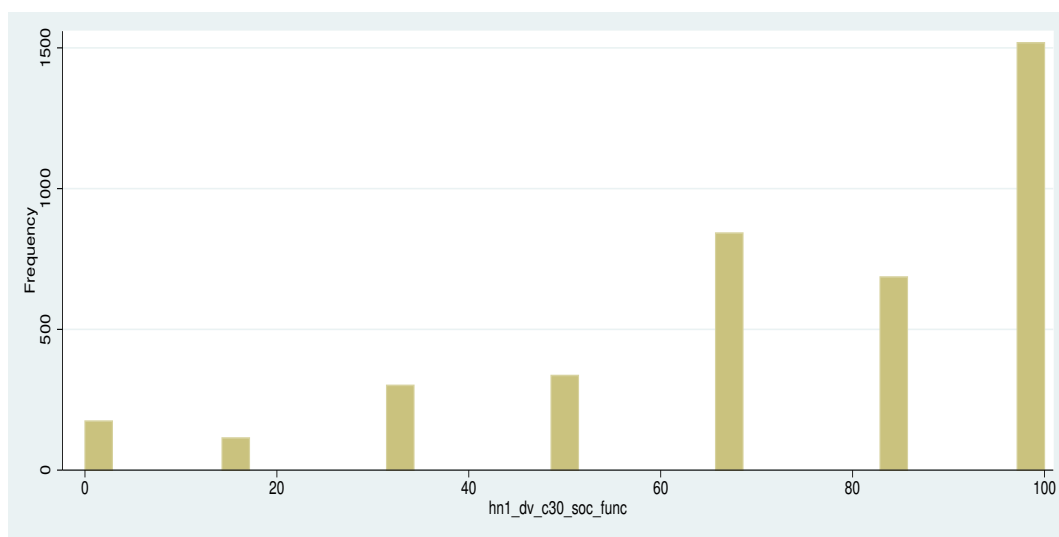
C dev5 Functional scale: Social Functioning*hn1_dv_c30_soc_func*

- **Stata code to derive variable:**

- $\text{gen hn1_dv_c30_soc_func} = (1 - (((\text{hn1_c26_ygh_family_life} + \text{hn1_c27_ygh_social_activ})/2) - 1)/3)) * 100$

- **Descriptives:**

- Total valid responses = 3971, number of missing values or data check errors = 67

Figure 27: Baseline - QLQ-C30: Functional scale: Social Functioning

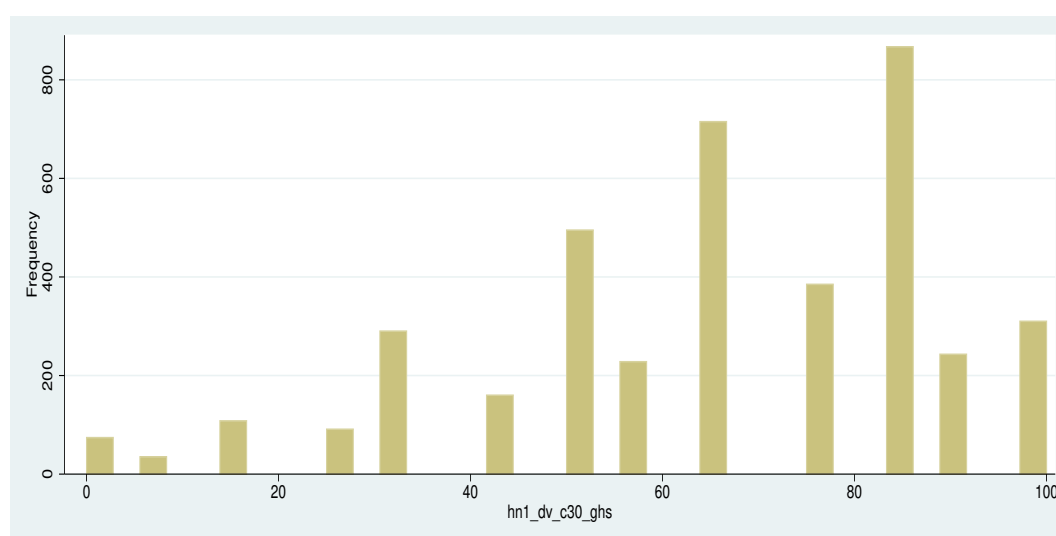
C dev6 Global Health Status/QoL*hn1_dv_c30_ghs*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_ghs = (((hn1_c29_ygh_health_past_wk + hn1_c30_ygh_lifequal_past_wk)/2)-1)/6)*100`

- **Descriptives:**

- Total valid responses = 4001, number of missing values or data check errors = 37

Figure 28: Baseline - QLQ-C30: Global Health Status/QoL

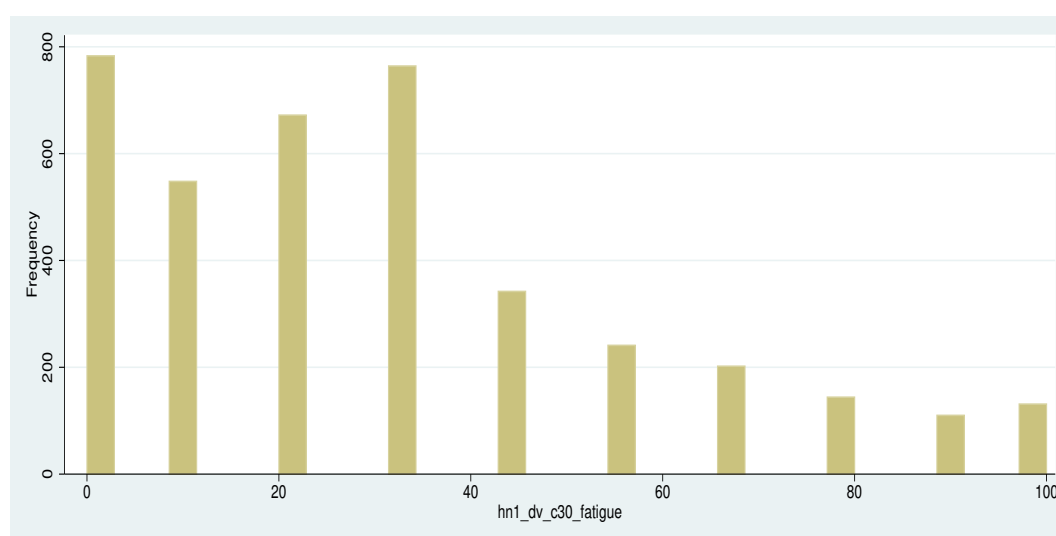
C dev7 Symptom scales/items: Fatigue*hn1_dv_c30_fatigue*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_fatigue = (((hn1_c10_ygh_need_to_rest + hn1_c12_ygh_felt_weak + hn1_c18_ygh_tired)/3)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3937, number of missing values or data check errors = 101

Figure 29: Baseline - QLQ-C30: Symptom scales/items: Fatigue

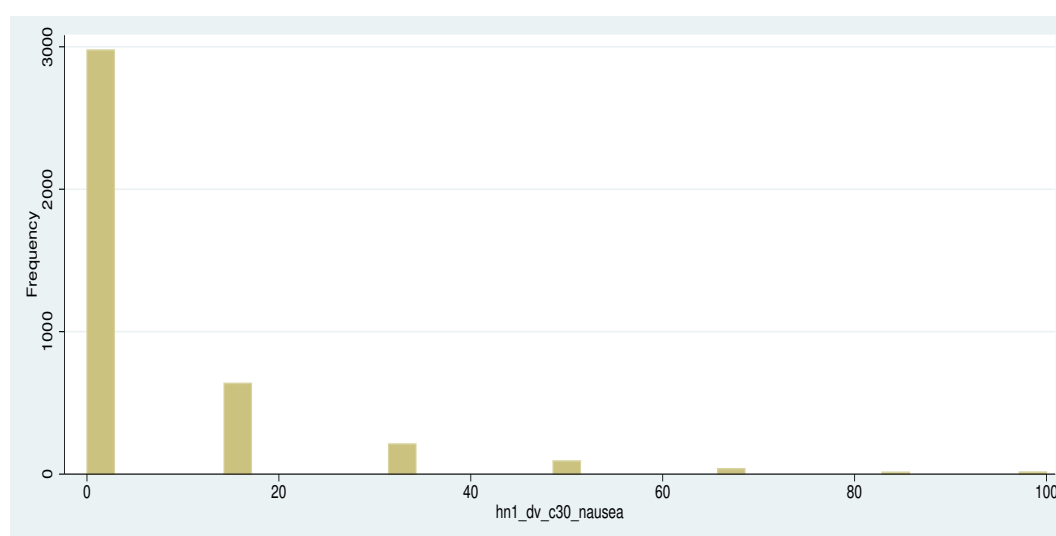
C dev8 Symptom scales/items: Nausea*hn1_dv_c30_nausea*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_nausea = (((hn1_c14_ygh_felt_nauseated + hn1_c15_ygh_vomited)/2)-1)/3*100`

- **Descriptives:**

- Total valid responses = 3981, number of missing values or data check errors = 57

Figure 30: Baseline - QLQ-C30: Symptom scales/items: Nausea

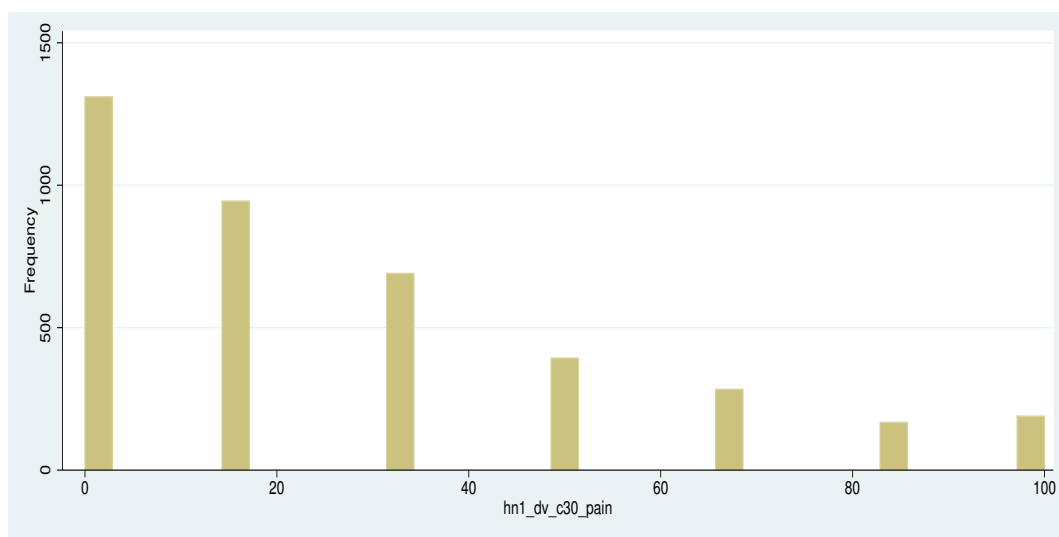
C dev9 Symptom scales/items: Pain*hn1_dv_c30_pain*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_pain = (((hn1_c9_ygh_had_pain + hn1_c19_ygh_pain_daily_activ)/2)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3976, number of missing values or data check errors = 62

Figure 31: Baseline - QLQ-C30: Symptom scales/items: Pain

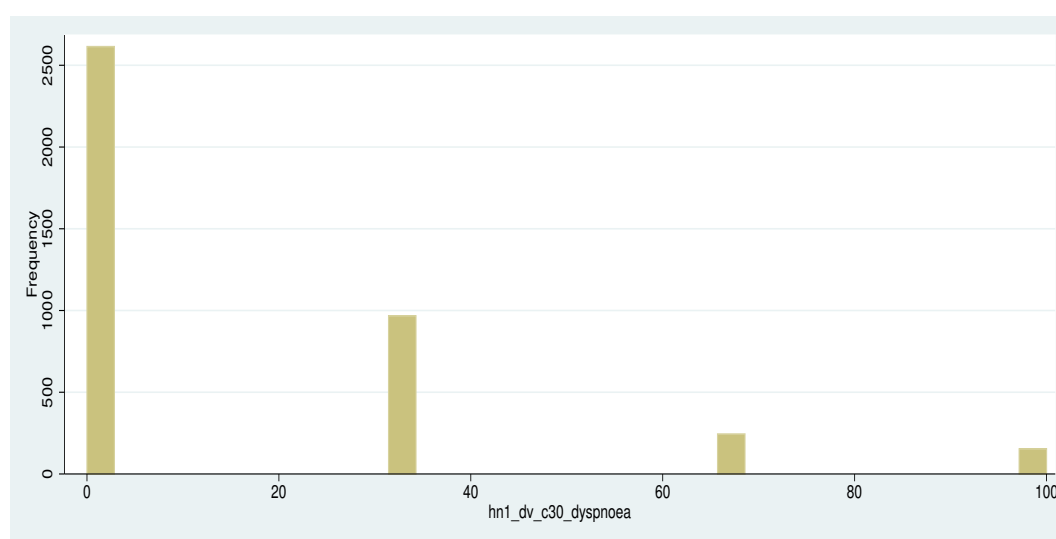
C dev10 Symptom scales/items: Dyspnoea*hn1_dv_c30_dyspnoea*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_dyspnoea = (((hn1_c8_ygh_short_of_breath)/1)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3978, number of missing values or data check errors = 60

Figure 32: Baseline - QLQ-C30: Symptom scales/items: Dyspnoea

C dev11 Symptom scales/items: Insomnia

hn1_dv_c30_insomnia

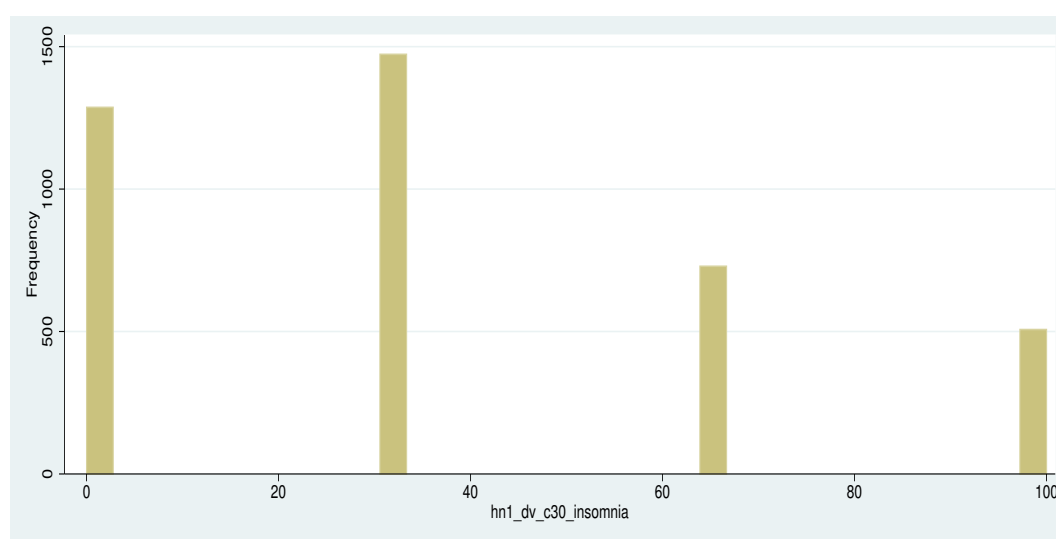
- **Stata code to derive variable:**

- `gen hn1_dv_c30_insomnia = (((hn1_c11_ygh_sleep_trouble)/1)-1)/3*100`

- **Descriptives:**

- Total valid responses = 3996, number of missing values or data check errors = 42

Figure 33: Baseline - QLQ-C30: Symptom scales/items: Insomnia



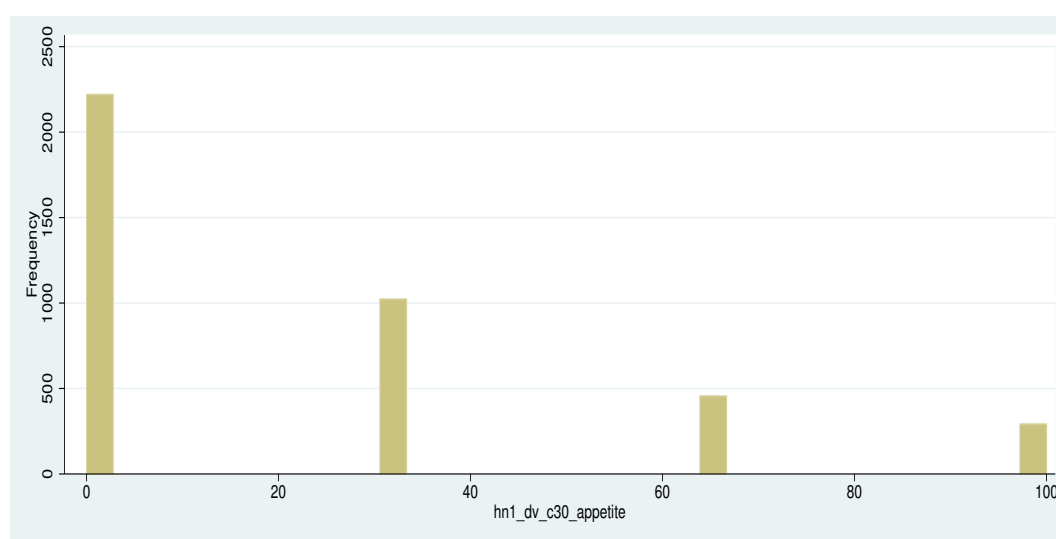
C dev12 Symptom scales/items: Appetite*hn1_dv_c30_appetite*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_appetite = (((hn1_c13_ygh_lacked_appetite)/1)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3991, number of missing values or data check errors = 47

Figure 34: Baseline - QLQ-C30: Symptom scales/items: Appetite

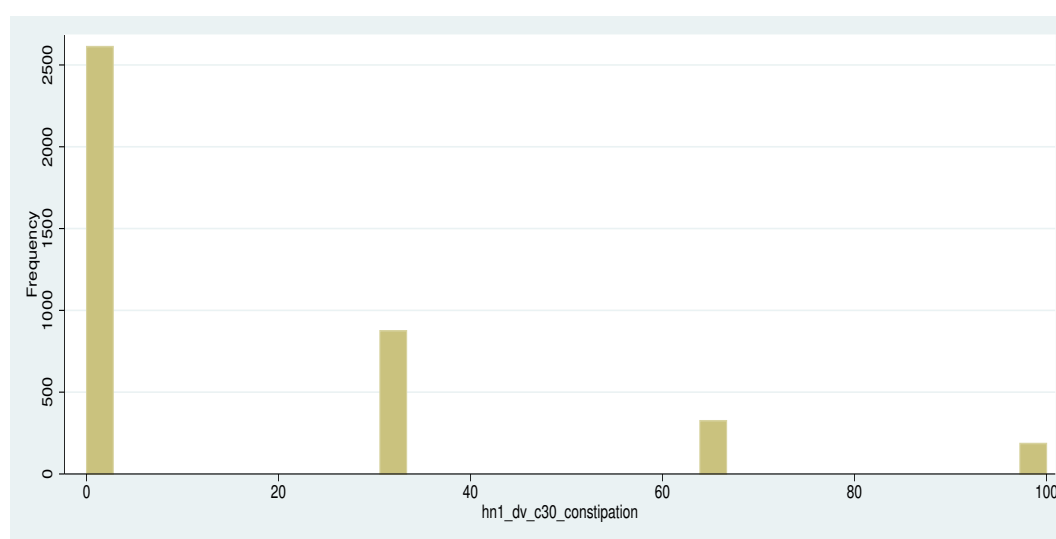
C dev13 Symptom scales/items: Constipation*hn1_dv_c30_constipation*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_constipation = (((hn1_c16_ygh_constipated)/1)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3998, number of missing values or data check errors = 40

Figure 35: Baseline - QLQ-C30: Symptom scales/items: Constipation

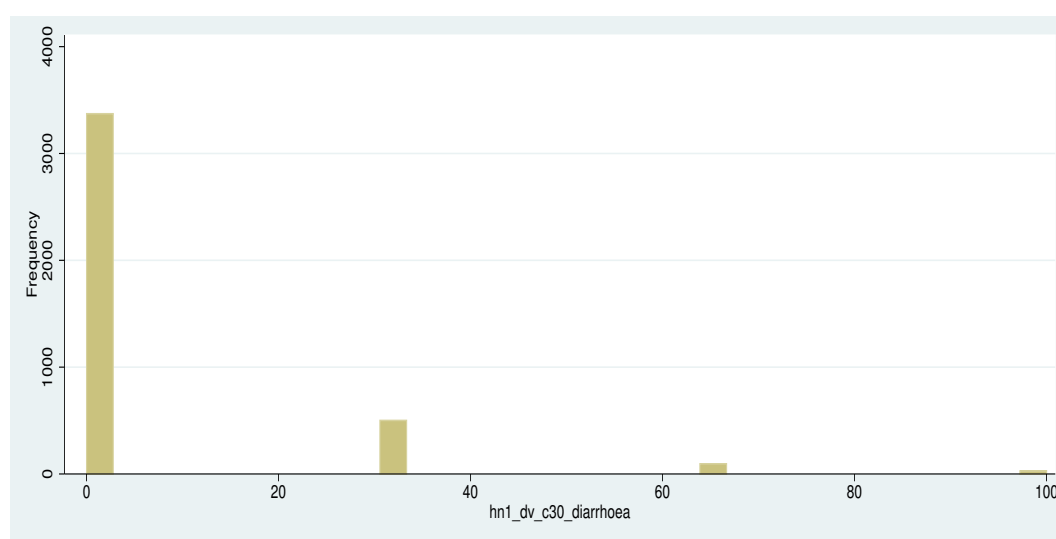
C dev14 Symptom scales/items: Diarrhoea*hn1_dv_c30_diarrhoea*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_diarrhoea = (((hn1_c17_ygh_diarrhoea)/1)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3996, number of missing values or data check errors = 42

Figure 36: Baseline - QLQ-C30: Symptom scales/items: Diarrhoea

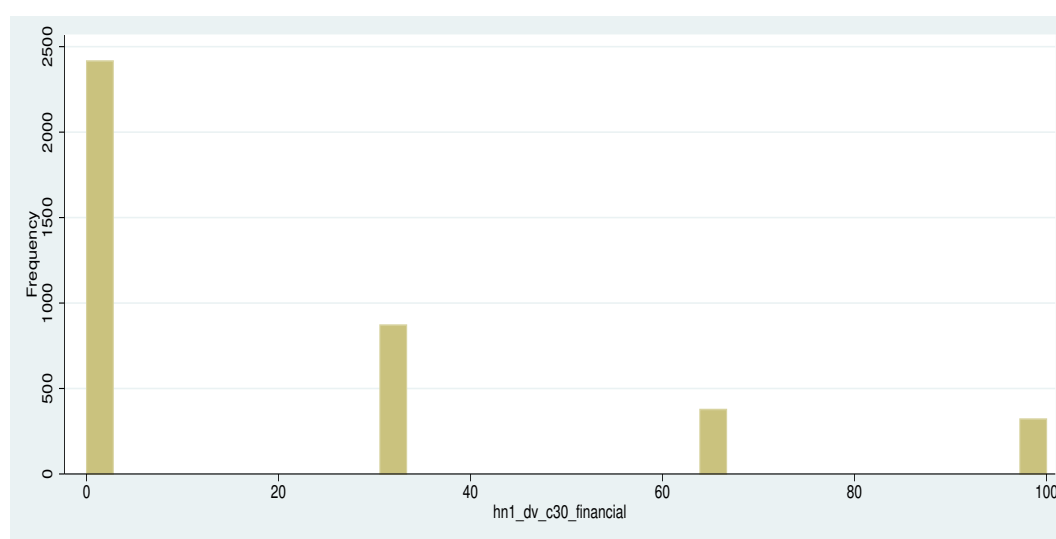
C dev15 Symptom scales/items: Financial*hn1_dv_c30_financial*

- **Stata code to derive variable:**

- `gen hn1_dv_c30_financial = (((hn1_c28_ygh_financial_diff)/1)-1)/3)*100`

- **Descriptives:**

- Total valid responses = 3985, number of missing values or data check errors = 53

Figure 37: Baseline - QLQ-C30: Symptom scales/items: Financial

3.2.6 Specific Aspects of Your health

The topics covered in the ‘Specific Aspects of Your health’ questionnaire are based on the ‘EORTC QLQ-H&N35’ questionnaire (Bjordal et al., 1993). Further details of the questionnaire used can be found in Appendix B.2.2 on page 475.

D1 Have you had pain in the mouth? - *hn1_d1_sayh_pain_mouth*

Table 78: Baseline - HN35: Have you had pain in the mouth?

BL - Have you had pain in your mouth:	No.	Col %	Cum %
1 - Not at all	1725	42.7	42.7
2 - A little	1218	30.2	72.9
3 - Quite a bit	646	16.0	88.9
4 - Very much	399	9.9	98.8
.a - Missing	50	1.2	100.0
Total	4038	100.0	

D2 Have you had pain in the jaw? - *hn1_d2_sayh_pain_jaw*

Table 79: Baseline - HN35: Have you had pain in the jaw?

BL - Have you had pain in your jaw:	No.	Col %	Cum %
1 - Not at all	2433	60.3	60.3
2 - A little	912	22.6	82.8
3 - Quite a bit	404	10.0	92.8
4 - Very much	206	5.1	97.9
.a - Missing	83	2.1	100.0
Total	4038	100.0	

D3 Have you had soreness in the mouth? - *hn1_d3_sayh_soreness_mouth*

Table 80: Baseline - HN35: Have you had soreness in the mouth?

BL - Have you had soreness in your mouth:	No.	Col %	Cum %
1 - Not at all	1791	44.4	44.4
2 - A little	1242	30.8	75.1
3 - Quite a bit	600	14.9	90.0
4 - Very much	342	8.5	98.4
.a - Missing	63	1.6	100.0
Total	4038	100.0	

D4 Have you had a painful throat? - *hn1_d4_sayh_painful_throat*

Table 81: Baseline - HN35: Have you had a painful throat?

BL - Have you had problems swallowing liquid:	No.	Col %	Cum %
1 - Not at all	1649	40.8	40.8
2 - A little	1406	34.8	75.7
3 - Quite a bit	577	14.3	89.9
4 - Very much	345	8.5	98.5
.a - Missing	61	1.5	100.0
Total	4038	100.0	

D5 Have you had problems swallowing liquid? - *hn1_d5_sayh_swallow_liquid*

Table 82: Baseline - HN35: Have you had problems swallowing liquid?

BL - Have you had problems swallowing liquid:	No.	Col %	Cum %
1 - Not at all	2811	69.6	69.6
2 - A little	730	18.1	87.7
3 - Quite a bit	256	6.3	94.0
4 - Very much	198	4.9	98.9
.a - Missing	43	1.1	100.0
Total	4038	100.0	

D6 Have you had problems swallowing pureed food? - *hn1_d6_sayh_swallow_pureed*

Table 83: Baseline - HN35: Have you had problems swallowing pureed food?

BL - Have you had problems swallowing pureed food:	No.	Col %	Cum %
1 - Not at all	3100	76.8	76.8
2 - A little	545	13.5	90.3
3 - Quite a bit	174	4.3	94.6
4 - Very much	131	3.2	97.8
.a - Missing	88	2.2	100.0
Total	4038	100.0	

D7 Have you had problems swallowing solid food? - *hn1_d7_sayh_swallow_solid*

Table 84: Baseline - HN35: Have you had problems swallowing solid food?

BL - Have you had problems swallowing solid food:	No.	Col %	Cum %
1 - Not at all	2292	56.8	56.8
2 - A little	881	21.8	78.6
3 - Quite a bit	383	9.5	88.1
4 - Very much	421	10.4	98.5
.a - Missing	61	1.5	100.0
Total	4038	100.0	

D8 Have you choked when swallowing? - *hn1_d8_sayh_choked*

Table 85: Baseline - HN35: Have you choked when swallowing?

BL - Have you choked when swallowing:	No.	Col %	Cum %
1 - Not at all	3417	84.6	84.6
2 - A little	409	10.1	94.7
3 - Quite a bit	96	2.4	97.1
4 - Very much	56	1.4	98.5
.a - Missing	60	1.5	100.0
Total	4038	100.0	

D9 Have you had problems with teeth? - *hn1_d9_sayh_problems_teeth***Table 86:** Baseline - HN35: Have you had problems with teeth?

BL - Have you had problems with your teeth:	No.	Col %	Cum %
1 - Not at all	2594	64.2	64.2
2 - A little	767	19.0	83.2
3 - Quite a bit	350	8.7	91.9
4 - Very much	243	6.0	97.9
.a - Missing	84	2.1	100.0
Total	4038	100.0	

D10 Have you had problems opening mouth? - *hn1_d10_sayh_open_mouth***Table 87:** Baseline - HN35: Have you had problems opening mouth?

BL - Have you had problems opening your mouth wide:	No.	Col %	Cum %
1 - Not at all	3009	74.5	74.5
2 - A little	595	14.7	89.3
3 - Quite a bit	235	5.8	95.1
4 - Very much	151	3.7	98.8
.a - Missing	48	1.2	100.0
Total	4038	100.0	

D11 Have you had a dry mouth? - *hn1_d11_sayh_dry_mouth***Table 88:** Baseline - HN35: Have you had a dry mouth?

BL - Have you had a dry mouth:	No.	Col %	Cum %
1 - Not at all	2019	50.0	50.0
2 - A little	1242	30.8	80.8
3 - Quite a bit	442	10.9	91.7
4 - Very much	287	7.1	98.8
.a - Missing	48	1.2	100.0
Total	4038	100.0	

D12 Have you had sticky saliva? - *hn1_d12_sayh_sticky_saliva***Table 89:** Baseline - HN35: Have you had sticky saliva?

BL - Have you had sticky saliva:	No.	Col %	Cum %
1 - Not at all	2406	59.6	59.6
2 - A little	930	23.0	82.6
3 - Quite a bit	390	9.7	92.3
4 - Very much	246	6.1	98.4
.a - Missing	66	1.6	100.0
Total	4038	100.0	

D13 Have you had problems with your sense of smell? - *hn1_d13_sayh_sense_smell*

Table 90: Baseline - HN35: Have you had problems with your sense of smell?

BL - Have you had problems with your sense of smell:	No.	Col %	Cum %
1 - Not at all	3238	80.2	80.2
2 - A little	491	12.2	92.3
3 - Quite a bit	133	3.3	95.6
4 - Very much	125	3.1	98.7
.a - Missing	51	1.3	100.0
Total	4038	100.0	

D14 Have you had problems with your sense of taste? - *hn1_d14_sayh_sense_taste*

Table 91: Baseline - HN35: Have you had problems with your sense of taste?

BL - Have you had problems with your sense of taste:	No.	Col %	Cum %
1 - Not at all	2772	68.6	68.6
2 - A little	784	19.4	88.1
3 - Quite a bit	270	6.7	94.7
4 - Very much	165	4.1	98.8
.a - Missing	47	1.2	100.0
Total	4038	100.0	

D15 Have you coughed? - *hn1_d15_sayh_coughed*

Table 92: Baseline - HN35: Have you coughed?

BL - Have you coughed:	No.	Col %	Cum %
1 - Not at all	1235	30.6	30.6
2 - A little	1984	49.1	79.7
3 - Quite a bit	568	14.1	93.8
4 - Very much	190	4.7	98.5
.a - Missing	61	1.5	100.0
Total	4038	100.0	

D16 Have you been hoarse? - *hn1_d16_sayh_hoarse*

Table 93: Baseline - HN35: Have you been hoarse?

BL - Have you been hoarse:	No.	Col %	Cum %
1 - Not at all	1954	48.4	48.4
2 - A little	1128	27.9	76.3
3 - Quite a bit	443	11.0	87.3
4 - Very much	420	10.4	97.7
.a - Missing	93	2.3	100.0
Total	4038	100.0	

D17 Have you felt ill? - *hn1_d17_sayh_felt_ill***Table 94:** Baseline - HN35: Have you felt ill?

BL - Have you felt ill:	No.	Col %	Cum %
1 - Not at all	2327	57.6	57.6
2 - A little	1198	29.7	87.3
3 - Quite a bit	311	7.7	95.0
4 - Very much	125	3.1	98.1
.a - Missing	77	1.9	100.0
Total	4038	100.0	

D18 Has your appearance bothered you? - *hn1_d18_sayh_appearance***Table 95:** Baseline - HN35: Has your appearance bothered you?

BL - Has your appearance bothered you:	No.	Col %	Cum %
1 - Not at all	2952	73.1	73.1
2 - A little	678	16.8	89.9
3 - Quite a bit	226	5.6	95.5
4 - Very much	129	3.2	98.7
.a - Missing	53	1.3	100.0
Total	4038	100.0	

D19 Have you had trouble eating? - *hn1_d19_sayh_trouble_eating***Table 96:** Baseline - HN35: Have you had trouble eating?

BL - Have you had trouble eating:	No.	Col %	Cum %
1 - Not at all	2244	55.6	55.6
2 - A little	974	24.1	79.7
3 - Quite a bit	399	9.9	89.6
4 - Very much	376	9.3	98.9
.a - Missing	45	1.1	100.0
Total	4038	100.0	

D20 Have you had trouble eating in front of family? - *hn1_d20_sayh_front_family***Table 97:** Baseline - HN35: Have you had trouble eating in front of family?

BL - Have you had trouble eating in front of family:	No.	Col %	Cum %
1 - Not at all	3267	80.9	80.9
2 - A little	368	9.1	90.0
3 - Quite a bit	147	3.6	93.7
4 - Very much	180	4.5	98.1
.a - Missing	76	1.9	100.0
Total	4038	100.0	

D21 Have you had trouble eating in front of others? - *hn1_d21_sayh_front_others*

Table 98: Baseline - HN35: Have you had trouble eating in front of others?

BL - Have you had trouble eating in front of others:	No.	Col %	Cum %
1 - Not at all	3106	76.9	76.9
2 - A little	447	11.1	88.0
3 - Quite a bit	180	4.5	92.4
4 - Very much	239	5.9	98.4
.a - Missing	66	1.6	100.0
Total	4038	100.0	

D22 Have you had trouble enjoying meals? - *hn1_d22_sayh_enjoying*

Table 99: Baseline - HN35: Have you had trouble enjoying meals?

BL - Have you had trouble enjoying meals:	No.	Col %	Cum %
1 - Not at all	2239	55.4	55.4
2 - A little	960	23.8	79.2
3 - Quite a bit	415	10.3	89.5
4 - Very much	375	9.3	98.8
.a - Missing	49	1.2	100.0
Total	4038	100.0	

D23 Have you had trouble talking to other people? - *hn1_d23_sayh_talking_people*

Table 100: Baseline - HN35: Have you had trouble talking to other people?

BL - Have you had trouble talking to other people:	No.	Col %	Cum %
1 - Not at all	2567	63.6	63.6
2 - A little	838	20.8	84.3
3 - Quite a bit	364	9.0	93.3
4 - Very much	224	5.5	98.9
.a - Missing	45	1.1	100.0
Total	4038	100.0	

D24 Have you had trouble talking on the telephone? - *hn1_d24_sayh_talking_phone*

Table 101: Baseline - HN35: Have you had trouble talking on the telephone?

BL - Have you had trouble talking on the telephone:	No.	Col %	Cum %
1 - Not at all	2483	61.5	61.5
2 - A little	812	20.1	81.6
3 - Quite a bit	385	9.5	91.1
4 - Very much	311	7.7	98.8
.a - Missing	47	1.2	100.0
Total	4038	100.0	

D25 Have you had trouble having social contact with family? - *hn1_d25_sayh_social_family*

Table 102: Baseline - HN35: Have you had trouble having social contact with family?

BL - Have you had trouble having social contact with family:	No.	Col %	Cum %
1 - Not at all	3269	81.0	81.0
2 - A little	466	11.5	92.5
3 - Quite a bit	135	3.3	95.8
4 - Very much	112	2.8	98.6
.a - Missing	56	1.4	100.0
Total	4038	100.0	

D26 Have you had trouble having social contact with friends? - *hn1_d26_sayh_social_friends*

Table 103: Baseline - HN35: Have you had trouble having social contact with friends?

BL - Have you had trouble having social contact with friends:	No.	Col %	Cum %
1 - Not at all	2984	73.9	73.9
2 - A little	662	16.4	90.3
3 - Quite a bit	203	5.0	95.3
4 - Very much	134	3.3	98.6
.a - Missing	55	1.4	100.0
Total	4038	100.0	

D27 Have you had trouble going out in public? - *hn1_d27_sayh_out_public*

Table 104: Baseline - HN35: Have you had trouble going out in public?

BL - Have you had trouble going out in public:	No.	Col %	Cum %
1 - Not at all	3246	80.4	80.4
2 - A little	439	10.9	91.3
3 - Quite a bit	176	4.4	95.6
4 - Very much	124	3.1	98.7
.a - Missing	53	1.3	100.0
Total	4038	100.0	

D28 Have you had trouble having physical contact with family or friends? - *hn1_d28_sayh_physical*

Table 105: Baseline - HN35: Have you had trouble having physical contact with family or friends?

BL - Have you had trouble having physical contact with family or friends:	No.	Col %	Cum %
1 - Not at all	3335	82.6	82.6
2 - A little	415	10.3	92.9
3 - Quite a bit	124	3.1	95.9
4 - Very much	87	2.2	98.1
.a - Missing	77	1.9	100.0
Total	4038	100.0	

D29 Have you felt less interest in sex? - *hn1_d29_sayh_sex*

Table 106: Baseline - HN35: Have you felt less interest in sex?

BL - Have you felt less interest in sex:	No.	Col %	Cum %
1 - Not at all	1569	38.9	38.9
2 - A little	838	20.8	59.6
3 - Quite a bit	591	14.6	74.2
4 - Very much	617	15.3	89.5
.a - Missing	423	10.5	100.0
Total	4038	100.0	

D30 Have you felt less sexual enjoyment? - *hn1_d30_sayh_sex_enjoy*

Table 107: Baseline - HN35: Have you felt less sexual enjoyment?

BL - Have you felt less sexual enjoyment:	No.	Col %	Cum %
1 - Not at all	1657	41.0	41.0
2 - A little	686	17.0	58.0
3 - Quite a bit	473	11.7	69.7
4 - Very much	581	14.4	84.1
.a - Missing	641	15.9	100.0
Total	4038	100.0	

D31 Have you used painkillers? - *hn1_d31_sayh_painkillers*

Table 108: Baseline - HN35: Have you used painkillers?

BL - Have you used painkillers:	No.	Col %	Cum %
1 - Yes	2552	63.2	63.2
2 - No	1448	35.9	99.1
.a - Missing	38	0.9	100.0
Total	4038	100.0	

D32 Have you taken any nutritional supplements (excluding vitamins)? - *hn1_d32_sayh_nutritional*

Table 109: Baseline - HN35: Have you taken any nutritional supplements (excluding vitamins)?

BL - Have you taken any nutritional supplements (excluding vitamins):	No.	Col %	Cum %
1 - Yes	889	22.0	22.0
2 - No	3067	76.0	98.0
.a - Missing	82	2.0	100.0
Total	4038	100.0	

D33 Have you used a feeding tube? - *hn1_d33_sayh_feed_tube*

Table 110: Baseline - HN35: Have you used a feeding tube?

BL - Have you used a feeding tube:	No.	Col %	Cum %
1 - Yes	195	4.8	4.8
2 - No	3784	93.7	98.5
.a - Missing	59	1.5	100.0
Total	4038	100.0	

D34 Have you lost weight? - *hn1_d34_sayh_lost_wght*

Table 111: Baseline - HN35: Have you lost weight?

BL - Have you lost weight:	No.	Col %	Cum %
1 - Yes	1164	28.8	28.8
2 - No	2770	68.6	97.4
.a - Missing	104	2.6	100.0
Total	4038	100.0	

D35 Have you gained weight? - *hn1_d35_sayh_gained_wght*

Table 112: Baseline - HN35: Have you gained weight?

BL - Have you gained weight:	No.	Col %	Cum %
1 - Yes	586	14.5	14.5
2 - No	3281	81.3	95.8
.a - Missing	171	4.2	100.0
Total	4038	100.0	

3.2.7 Your Feelings

The topics covered in the ‘Your Feelings’ questionnaire are based on the ‘Hospital Anxiety and Depression Scale (HADS)’ questionnaire (Zigmond and Snaith, 1983). Further details of the questionnaire used can be found in Appendix B.2.2 on page 475.

E1 I feel tense or 'wound up': - *hn1_e1_yf_tense*

Table 113: Baseline - HADS: I feel tense or 'wound up'

BL - I feel tense or wound up:	No.	Col %	Cum %
1 - Most of the time	251	6.2	6.2
2 - A lot of the time	506	12.5	18.7
3 - From time to time occasionally	2342	58.0	76.7
4 - Not at all	906	22.4	99.2
.a - Missing	33	0.8	100.0
Total	4038	100.0	

E2 I still enjoy the things I used to enjoy: - *hn1_e2_yf_enjoy*

Table 114: Baseline - HADS: I still enjoy the things I used to enjoy

BL - I still enjoy the things I used to enjoy:	No.	Col %	Cum %
1 - Definitely as much	1839	45.5	45.5
2 - Not quite so much	1582	39.2	84.7
3 - Only a little	368	9.1	93.8
4 - Hardly at all	210	5.2	99.0
.a - Missing	39	1.0	100.0
Total	4038	100.0	

E3 I get a sort of frightened feeling as if something awful is about to happen: - *hn1_e3_yf_frightened*

Table 115: Baseline - HADS: I get a sort of frightened feeling as if something awful is about to happen

BL - I get a sort of frightened feeling as if something awful is about to happen	No.	Col %	Cum %
1 - Very definitely and quite badly	373	9.2	9.2
2 - Yes but not to badly	1073	26.6	35.8
3 - A little but it does not worry me	1413	35.0	70.8
4 - Not at all	1142	28.3	99.1
.a - Missing	37	0.9	100.0
Total	4038	100.0	

E4 I can laugh and see the funny side of things: - *hn1_e4_yf_laugh*

Table 116: Baseline - HADS: I can laugh and see the funny side of things

BL - I can laugh and see the funny side of things:	No.	Col %	Cum %
1 - As much as I always could	2815	69.7	69.7
2 - Not quite so much now	943	23.4	93.1
3 - Definitely not so much now	192	4.8	97.8
4 - Not at all	57	1.4	99.2
.a - Missing	31	0.8	100.0
Total	4038	100.0	

E5 Worrying thoughts go through my mind: - *hn1_e5_yf_worrying***Table 117:** Baseline - HADS: Worrying thoughts go through my mind

BL - Worrying thoughts go through my mind:	No.	Col %	Cum %
1 - A great deal of the time	416	10.3	10.3
2 - A lot of the time	766	19.0	29.3
3 - From time to time but not too often	1695	42.0	71.2
4 - Only occasionally	1121	27.8	99.0
.a - Missing	40	1.0	100.0
Total	4038	100.0	

E6 I feel cheerful: - *hn1_e6_yf_cheerful***Table 118:** Baseline - HADS: I feel cheerful

BL - I feel cheerful:	No.	Col %	Cum %
1 - Not at all	87	2.2	2.2
2 - Not often	279	6.9	9.1
3 - Sometimes	1281	31.7	40.8
4 - Most of the time	2362	58.5	99.3
.a - Missing	29	0.7	100.0
Total	4038	100.0	

E7 I can sit at ease and feel relaxed: - *hn1_e7_yf_at_ease***Table 119:** Baseline - HADS: I can sit at ease and feel relaxed

BL - I can sit at ease and feel relaxed:	No.	Col %	Cum %
1 - Definitely	1276	31.6	31.6
2 - Usually	2022	50.1	81.7
3 - Not Often	628	15.6	97.2
4 - Not at all	76	1.9	99.1
.a - Missing	36	0.9	100.0
Total	4038	100.0	

E8 I feel as if I am slowed down: - *hn1_e8_yf_slowed***Table 120:** Baseline - HADS: I feel as if I am slowed down

BL - I feel as if I am slowed down:	No.	Col %	Cum %
1 - Nearly all the time	413	10.2	10.2
2 - Very often	692	17.1	27.4
3 - Sometimes	1827	45.2	72.6
4 - Not at all	1072	26.5	99.2
.a - Missing	34	0.8	100.0
Total	4038	100.0	

E9 I get a sort of frightened feeling like 'butterflies' in the stomach: - *hn1_e9_yf_butterflies*

Table 121: Baseline - HADS: I get a sort of frightened feeling like 'butterflies' in the stomach

BL - I get a sort of frightened feeling like butterflies in the stomach:	No.	Col %	Cum %
1 - Not at all	1715	42.5	42.5
2 - Occasionally	1818	45.0	87.5
3 - Quite often	351	8.7	96.2
4 - Very often	113	2.8	99.0
.a - Missing	41	1.0	100.0
Total	4038	100.0	

E10 I have lost interest in my appearance: - *hn1_e10_yf_appearance*

Table 122: Baseline - HADS: I have lost interest in my appearance

BL - I have lost interest in my appearance:	No.	Col %	Cum %
1 - Definitely	103	2.6	2.6
2 - I don't take as much care as I should	369	9.1	11.7
3 - I may not take quite as much care	792	19.6	31.3
4 - I take just as much care as ever	2738	67.8	99.1
.a - Missing	36	0.9	100.0
Total	4038	100.0	

E11 I feel restless as I have to be on the move: - *hn1_e11_yf_restless*

Table 123: Baseline - HADS: I feel restless as I have to be on the move

BL - I feel restless as I have to be on the move:	No.	Col %	Cum %
1 - Very much indeed	254	6.3	6.3
2 - Quite a lot	1125	27.9	34.2
3 - Not very much	1502	37.2	71.3
4 - Not at all	1106	27.4	98.7
.a - Missing	51	1.3	100.0
Total	4038	100.0	

E12 I look forward with enjoyment to things: - *hn1_e12_yf_enjoyment*

Table 124: Baseline - HADS: I look forward with enjoyment to things

BL - I look forward with enjoyment to things:	No.	Col %	Cum %
1 - As much as I ever did	2259	55.9	55.9
2 - Rather less than I used to	1185	29.3	85.3
3 - Definitely less than I used to	443	11.0	96.3
4 - Hardly at all	103	2.6	98.8
.a - Missing	48	1.2	100.0
Total	4038	100.0	

E13 I get sudden feelings of panic: - *hn1_e13_yf_panic*

Table 125: Baseline - HADS: I get sudden feelings of panic

BL - I get sudden feelings of panic:	No.	Col %	Cum %
1 - Very often indeed	115	2.8	2.8
2 - Quite often	484	12.0	14.8
3 - Not very often	1484	36.8	51.6
4 - Not at all	1902	47.1	98.7
.a - Missing	53	1.3	100.0
Total	4038	100.0	

E14 I can enjoy a good book or radio or TV program: - *hn1_e14_yf_book*

Table 126: Baseline - HADS: I can enjoy a good book or radio or TV program

BL - I can enjoy a good book or radio or TV program:	No.	Col %	Cum %
1 - Often	2822	69.9	69.9
2 - Sometimes	871	21.6	91.5
3 - Not often	182	4.5	96.0
4 - Very seldom	110	2.7	98.7
.a - Missing	53	1.3	100.0
Total	4038	100.0	

3.2.8 Your Diet

F1 In summary, how many servings of fruit do you usually eat, not counting juices? - *hn1_f1_yd_servings_fruit*

Table 127: Baseline - YD: How many servings of fruit do you usually eat, not counting juices?

BL - How many servings of fruit do you usually eat	No.	Col %	Cum %
1 - None	214	5.3	5.3
2 - Less than one per month	193	4.8	10.1
3 - 1-3per month	310	7.7	17.8
4 - 1 per week	360	8.9	26.7
5 - 2-4 per week	745	18.4	45.1
6 - 5-6 per week	324	8.0	53.1
7 - 1 per day	578	14.3	67.5
8 - 2-3 per day	968	24.0	91.4
9 - 4-5 per day	239	5.9	97.4
10 - 6 or more per day	51	1.3	98.6
.a - Missing	56	1.4	100.0
Total	4038	100.0	

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

- *hn1_f2_yd_servings_veg*

Table 128: Baseline - YD: How many servings of vegetables do you usually eat, not counting salad or potatoes?

BL - How many servings of vegetables do you usually eat	No.	Col %	Cum %
1 - None	76	1.9	1.9
2 - Less than one per month	52	1.3	3.2
3 - 1-3per month	84	2.1	5.3
4 - 1 per week	145	3.6	8.8
5 - 2-4 per week	912	22.6	31.4
6 - 5-6 per week	595	14.7	46.2
7 - 1 per day	510	12.6	58.8
8 - 2-3 per day	1336	33.1	91.9
9 - 4-5 per day	239	5.9	97.8
10 - 6 or more per day	28	0.7	98.5
.a - Missing	61	1.5	100.0
Total	4038	100.0	

F3 In summary, how often do you eat deep fried food (e.g. French fries, fried chicken, fried fish, fried clams, fried shrimp etc.)? - *hn1_f3_yd_deepfried_food*

Table 129: Baseline - YD: How often do you eat deep fried food?

BL - How often do you eat deep fried food	No.	Col %	Cum %
1 - Never	522	12.9	12.9
2 - Less than once per week	1502	37.2	50.1
3 - Once per week	1097	27.2	77.3
4 - 2-4 times per week	765	18.9	96.2
5 - 5-6 times per week	47	1.2	97.4
6 - Daily	20	0.5	97.9
.a - Missing	85	2.1	100.0
Total	4038	100.0	

3.2.9 Your Quality of Life

The topics covered in the ‘Your Quality of Life’ questionnaire are based on the revised ‘University of Washington (UW) QoL’ questionnaire (Hassan and Weymuller, 1993; Rogers et al., 2002). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.2.3 on page 489.

I1 Pain - *hn1_i1_yql_pain***Table 130:** Baseline - UWQoL - Pain

BL - Pain:	No.	Col %	Cum %
1 - I have no pain	81	24.3	24.3
2 - There is mild pain not needing medication	96	28.8	53.2
3 - I have moderate pain(reg medication)	127	38.1	91.3
4 - I have severe pain controlled only by prescription medicine	23	6.9	98.2
5 - I have severe pain not controlled by medication	4	1.2	99.4
.a - Missing	2	0.6	100.0
Total	333	100.0	

I2 Appearance - *hn1_i2_yql_appearance***Table 131:** Baseline - UWQoL - Appearance

BL - Appearance	No.	Col %	Cum %
1 - There is no change in my appearance	193	58.0	58.0
2 - The change in my appearance is minor	109	32.7	90.7
3 - My appearance bothers me but I remain active	23	6.9	97.6
4 - I feel significantly disfigured and limit my activities due to my appearance	3	0.9	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

I3 Activity - *hn1_i3_yql_activity***Table 132:** Baseline - UWQoL - A

BL - Activity	No.	Col %	Cum %
1 - I am as active as I have ever been	125	37.5	37.5
2 - There are times when I cannot keep up my old pace but not often	91	27.3	64.9
3 - I am often tired and have slowed down my activities although I still get out	105	31.5	96.4
4 - I donot go out because I donot have the strength	3	0.9	97.3
5 - I am usually in bed or chair and donot leave home	7	2.1	99.4
.a - Missing	2	0.6	100.0
Total	333	100.0	

I4 Recreation - *hn1_i4_yql_recreation***Table 133:** Baseline - UWQoL - Recreation

BL - Recreation	No.	Col %	Cum %
1 - There are no limitations to recreation at home or away from home	131	39.3	39.3
2 - There are a few things I cannot do but I still get out and enjoy life	127	38.1	77.5
3 - There are many times when I wish I could get out more but I am not up to it	48	14.4	91.9
4 - There are severe limitations to what I can do mostly I stay at home and watch TV	17	5.1	97.0
5 - I cannot do anything enjoyable	5	1.5	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

I5 Swallowing - *hn1_i5_yql_swallowing***Table 134:** Baseline - UWQoL - Swallowing

BL - Swallowing:	No.	Col %	Cum %
1 - I can swallow as well as ever	217	65.2	65.2
2 - I cannot swallow certain solid foods	91	27.3	92.5
3 - I can only swallow liquid food	13	3.9	96.4
4 - I cannot swallow because it goes down the wrong way and chokes me	4	1.2	97.6
.a - Missing	8	2.4	100.0
Total	333	100.0	

I6 Chewing - *hn1_i6_yql_chewing***Table 135:** Baseline - UWQoL - Chewing

BL - Chewing:	No.	Col %	Cum %
1 - I can chew as well as ever	207	62.2	62.2
2 - I can eat soft solids but cannot chew some foods	101	30.3	92.5
3 - I cannot even chew soft solids	16	4.8	97.3
.a - Missing	9	2.7	100.0
Total	333	100.0	

I7 Speech - *hn1_i7_yql_speech***Table 136:** Baseline - UWQoL - Speech

BL - Speech:	No.	Col %	Cum %
1 - My speech is the same as always	228	68.5	68.5
2 - I have difficulty with saying some words but I can be understood over the phone	84	25.2	93.7
3 - Only my family and friends can understand me	7	2.1	95.8
4 - Only my family and friends can understand me	4	1.2	97.0
.a - Missing	10	3.0	100.0
Total	333	100.0	

I8 Shoulder - *hn1_i8_yql_shoulder***Table 137:** Baseline - UWQoL - Shoulder

BL - Shoulder	No.	Col %	Cum %
1 - I have no problem with my shoulder	267	80.2	80.2
2 - My shoulder is stiff but it has not affected my activity or strength	44	13.2	93.4
3 - Pain or weakness in my shoulder has caused me to change my work	10	3.0	96.4
4 - I cannot work due to problems with my shoulder	4	1.2	97.6
.a - Missing	8	2.4	100.0
Total	333	100.0	

I9 Taste - *hn1_i9_yql_taste***Table 138:** Baseline - UWQoL - Taste

BL - Taste:	No.	Col %	Cum %
1 - I can taste food normally	221	66.4	66.4
2 - I can taste most foods normally	70	21.0	87.4
3 - I can taste some foods	28	8.4	95.8
4 - I cannot taste any foods	10	3.0	98.8
.a - Missing	4	1.2	100.0
Total	333	100.0	

I10 Saliva - *hn1_i10_yql_saliva***Table 139:** Baseline - UWQoL - Saliva

BL - Saliva:	No.	Col %	Cum %
1 - My saliva is of normal consistency	248	74.5	74.5
2 - I have less saliva than normal but it is enough	55	16.5	91.0
3 - I have too little saliva	17	5.1	96.1
4 - I have no saliva	3	0.9	97.0
.a - Missing	10	3.0	100.0
Total	333	100.0	

I11 Mood - *hn1_i11_yql_mood***Table 140:** Baseline - UWQoL - Mood

BL - Mood	No.	Col %	Cum %
1 - My mood is excellent and unaffected by my cancer	85	25.5	25.5
2 - My mood is generally good and only occasionally affected by my cancer	160	48.0	73.6
3 - I am neither in a good mood nor depressed about my cancer	34	10.2	83.8
4 - I am somewhat depressed about my cancer	39	11.7	95.5
5 - I am extremely depressed about my cancer	8	2.4	97.9
.a - Missing	7	2.1	100.0
Total	333	100.0	

I12 Anxiety - *hn1_i12_yql_anxiety***Table 141:** Baseline - UWQoL - Anxiety

BL - Anxiety:	No.	Col %	Cum %
1 - I am not anxious about my cancer	48	14.4	14.4
2 - I am a little anxious about my cancer	175	52.6	67.0
3 - I am anxious about my cancer	81	24.3	91.3
4 - I am very anxious about my cancer	25	7.5	98.8
.a - Missing	4	1.2	100.0
Total	333	100.0	

I13A (1) Which issues have been the most important to you during the past 7 days? - *hn1_i13a_yql_issues***Table 142:** Baseline - UWQoL - (1) Which issues have been the most important to you during the past 7 days?

BL - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
1 - Pain	149	44.7	44.7
2 - Appearance	39	11.7	56.5
3 - Activity	34	10.2	66.7
4 - Recreation	8	2.4	69.1
5 - Swallowing	23	6.9	76.0
6 - Chewing	10	3.0	79.0
7 - Speech	9	2.7	81.7
8 - Shoulder	3	0.9	82.6
9 - Taste	2	0.6	83.2
10 - Saliva	1	0.3	83.5
11 - Mood	18	5.4	88.9
12 - Anxiety	15	4.5	93.4
.a - Missing	22	6.6	100.0
Total	333	100.0	

I13B (2) Which issues have been the most important to you during the past 7 days? - *hn1_i13b_yql_issues***Table 143:** Baseline - UWQoL - (2) Which issues have been the most important to you during the past 7 days?

BL - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
2 - Appearance	14	4.2	4.2
3 - Activity	35	10.5	14.7
4 - Recreation	21	6.3	21.0
5 - Swallowing	54	16.2	37.2
6 - Chewing	30	9.0	46.2
7 - Speech	21	6.3	52.6
8 - Shoulder	11	3.3	55.9
9 - Taste	6	1.8	57.7
10 - Saliva	10	3.0	60.7
11 - Mood	28	8.4	69.1
12 - Anxiety	21	6.3	75.4
.a - Missing	82	24.6	100.0
Total	333	100.0	

I13C (3) Which issues have been the most important to you during the past 7 days? - *hn1_i13c_yql_issues*

Table 144: Baseline - UWQoL - (3) Which issues have been the most important to you during the past 7 days?

BL - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
3 - Activity	1	0.3	0.3
4 - Recreation	15	4.5	4.8
5 - Swallowing	11	3.3	8.1
6 - Chewing	14	4.2	12.3
7 - Speech	27	8.1	20.4
8 - Shoulder	5	1.5	21.9
9 - Taste	10	3.0	24.9
10 - Saliva	15	4.5	29.4
11 - Mood	25	7.5	36.9
12 - Anxiety	69	20.7	57.7
.a - Missing	141	42.3	100.0
Total	333	100.0	

I14 Compared to the month before you developed cancer, how would you rate your health-related quality of life? - *hn1_i14_yql_qol_month*

Table 145: Baseline - UWQoL - Compared to the month before you developed cancer, how would you rate your health-related quality of life?

BL - Compared to the month before you developed cancer, how would you rate your	No.	Col %	Cum %
1 - Much better	24	7.2	7.2
2 - Somewhat better	31	9.3	16.5
3 - About the same	199	59.8	76.3
4 - Somewhat worse	59	17.7	94.0
5 - Much worse	13	3.9	97.9
.a - Missing	7	2.1	100.0
Total	333	100.0	

I15 In general, would you say your health-related quality of life during the past 7 days has been: - *hn1_i15_yql_qol_7_days*

Table 146: Baseline - UWQoL - In general, would you say your health-related quality of life during the past 7 days has been:

BL - In general, would you say your health-related quality of life during the	No.	Col %	Cum %
1 - Outstanding	6	1.8	1.8
2 - Very good	90	27.0	28.8
3 - Good	124	37.2	66.1
4 - Fair	78	23.4	89.5
5 - Poor	24	7.2	96.7
6 - Very Poor	9	2.7	99.4
.a - Missing	2	0.6	100.0
Total	333	100.0	

I16 Overall quality of life during the past 7 days - *hn1_i16_yql_well_being***Table 147:** Baseline - UWQoL - Overall quality of life during the past 7 days

BL - Considering everything in your life that contributes to your personal well-	No.	Col %	Cum %
1 - Outstanding	14	4.2	4.2
2 - Very good	112	33.6	37.8
3 - Good	109	32.7	70.6
4 - Fair	69	20.7	91.3
5 - Poor	23	6.9	98.2
6 - Very poor	2	0.6	98.8
.a - Missing	4	1.2	100.0
Total	333	100.0	

I17A 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. - *hn1_i17_yql_items*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

3.2.10 Difficulties in Your Life

The topics covered in the ‘Difficulties in Your Life’ questionnaire are based on the ‘Social difficulties Inventory (SDI)’ questionnaire (Wright et al., 2005). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.2.3 on page 489.

J1 Have you had any difficulty maintaining your independence? - *hn1_j1_dyl_independence*

Table 148: Baseline - SDI - Have you had any difficulty maintaining your independence?

BL - Have you had any difficulty maintaining your independence:	No.	Col %	Cum %
1 - No difficulty	253	76.0	76.0
2 - A little	56	16.8	92.8
3 - Quite a bit	16	4.8	97.6
4 - Very much	5	1.5	99.1
.a - Missing	3	0.9	100.0
Total	333	100.0	

J2 Have you had any difficulty in carrying out your domestic chores? - *hn1_j2_dyl_dom_chores*

Table 149: Baseline - SDI - Have you had any difficulty in carrying out your domestic chores?

BL - Have you had any difficulty in carrying out your domestic chores? (e.g. cle	No.	Col %	Cum %
1 - No difficulty	216	64.9	64.9
2 - A little	75	22.5	87.4
3 - Quite a bit	24	7.2	94.6
4 - Very much	12	3.6	98.2
.a - Missing	6	1.8	100.0
Total	333	100.0	

J3 Have you had any difficulty with managing your own personal care? - *hn1_j3_dyl_personal_care*

Table 150: Baseline - SDI - Have you had any difficulty with managing your own personal care?

BL - Have you had any difficulty with managing your own personal care? (e.g. bat	No.	Col %	Cum %
1 - No difficulty	287	86.2	86.2
2 - A little	36	10.8	97.0
3 - Quite a bit	6	1.8	98.8
4 - Very much	2	0.6	99.4
.a - Missing	2	0.6	100.0
Total	333	100.0	

J4 Have you had any difficulty with looking after those who depend on you? - *hn1_j4_dyl_dependents*

Table 151: Baseline - SDI - Have you had any difficulty with looking after those who depend on you?

BL - Have you had any difficulty with looking after those who depend on you? (e.	No.	Col %	Cum %
1 - No difficulty	272	81.7	81.7
2 - A little	31	9.3	91.0
3 - Quite a bit	4	1.2	92.2
4 - Very much	7	2.1	94.3
.a - Missing	19	5.7	100.0
Total	333	100.0	

J5 Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them? - *hn1_j5_dyl_support*

Table 152: Baseline - SDI - Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?

BL - Have any of those close to you (e.g. partner, children, parents) had any di	No.	Col %	Cum %
1 - No difficulty	285	85.6	85.6
2 - A little	24	7.2	92.8
3 - Quite a bit	6	1.8	94.6
4 - Very much	2	0.6	95.2
.a - Missing	16	4.8	100.0
Total	333	100.0	

J6 Have you had any difficulties with benefits? - *hn1_j6_dyl_benefits*

Table 153: Baseline - SDI - Have you had any difficulties with benefits?

BL - Have you had any difficulties with benefits? (e.g. statutory sick pay, atte	No.	Col %	Cum %
1 - No difficulty	269	80.8	80.8
2 - A little	27	8.1	88.9
3 - Quite a bit	12	3.6	92.5
4 - Very much	5	1.5	94.0
.a - Missing	20	6.0	100.0
Total	333	100.0	

J7 Have you had any financial difficulties? - *hn1_j7_dyl_financial_dif*

Table 154: Baseline - SDI - Have you had any financial difficulties?

BL - Have you had any financial difficulties:	No.	Col %	Cum %
1 - No difficulty	224	67.3	67.3
2 - A little	60	18.0	85.3
3 - Quite a bit	22	6.6	91.9
4 - Very much	13	3.9	95.8
.a - Missing	14	4.2	100.0
Total	333	100.0	

J8 Have you had any difficulties with financial services? - *hn1_j8_dyl_financial_service*

Table 155: Baseline - SDI - Have you had any difficulties with financial services?

BL - Have you had any difficulties with financial services? (e.g. loans, mortgag	No.	Col %	Cum %
1 - No difficulty	285	85.6	85.6
2 - A little	22	6.6	92.2
3 - Quite a bit	12	3.6	95.8
4 - Very much	6	1.8	97.6
.a - Missing	8	2.4	100.0
Total	333	100.0	

J9 Have you had any difficulty concerning your work? - *hn1_j9_dyl_difficulty_work*

Table 156: Baseline - SDI - Have you had any difficulty concerning your work?

BL - Have you had any difficulty concerning your work? (or education if you are	No.	Col %	Cum %
1 - No difficulty	234	70.3	70.3
2 - A little	40	12.0	82.3
3 - Quite a bit	18	5.4	87.7
4 - Very much	14	4.2	91.9
.a - Missing	27	8.1	100.0
Total	333	100.0	

J10 Have you had any difficulty with planning for your own or your family's future? - *hn1_j10_dyl_dif_plan_future*

Table 157: Baseline - SDI - Have you had any difficulty with planning for your own or your family's future?

BL - Have you had any difficulty with planning for your own or your family's fut	No.	Col %	Cum %
1 - No difficulty	260	78.1	78.1
2 - A little	42	12.6	90.7
3 - Quite a bit	11	3.3	94.0
4 - Very much	9	2.7	96.7
.a - Missing	11	3.3	100.0
Total	333	100.0	

J11 Have you had any difficulty communicating with those closest to you? - *hn1_j11_dyl_com_closest*

Table 158: Baseline - SDI - Have you had any difficulty communicating with those closest to you?

BL - Have you had any difficulty communicating with those closest to you? (e.g.	No.	Col %	Cum %
1 - No difficulty	261	78.4	78.4
2 - A little	57	17.1	95.5
3 - Quite a bit	5	1.5	97.0
4 - Very much	5	1.5	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

J12 Have you had difficulty communicating with others? - *hn1_j12_dyl_com_others*

Table 159: Baseline - SDI - Have you had difficulty communicating with others?

BL - Have you had difficulty communicating with others? (e.g. friends, neighbour	No.	Col %	Cum %
1 - No difficulty	244	73.3	73.3
2 - A little	68	20.4	93.7
3 - Quite a bit	12	3.6	97.3
4 - Very much	4	1.2	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

J13 Have you had any difficulty concerning sexual matters? - *hn1_j13_dyl_sexual_matters*

Table 160: Baseline - SDI - Have you had any difficulty concerning sexual matters?

BL - Have you had any difficulty concerning sexual matters:	No.	Col %	Cum %
1 - No difficulty	241	72.4	72.4
2 - A little	41	12.3	84.7
3 - Quite a bit	11	3.3	88.0
4 - Very much	11	3.3	91.3
.a - Missing	29	8.7	100.0
Total	333	100.0	

J14 Have you had any difficulty concerning plans to have a family? - *hn1_j14_dyl_dif_having_fam*

Table 161: Baseline - SDI - Have you had any difficulty concerning plans to have a family?

BL - Have you had any difficulty concerning plans to have a family:	No.	Col %	Cum %
1 - No difficulty	274	82.3	82.3
2 - A little	7	2.1	84.4
3 - Quite a bit	3	0.9	85.3
4 - Very much	3	0.9	86.2
.a - Missing	46	13.8	100.0
Total	333	100.0	

J15 Have you had any difficulty concerning your appearance or body image? - *hn1_j15_dyl_body_image*

Table 162: Baseline - SDI - Have you had any difficulty concerning your appearance or body image?

BL - Have you had any difficulty concerning your appearance or body image:	No.	Col %	Cum %
1 - No difficulty	251	75.4	75.4
2 - A little	63	18.9	94.3
3 - Quite a bit	8	2.4	96.7
4 - Very much	6	1.8	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

J16 Have you felt isolated? - *hn1_j16_dyl_felt_isolated*

Table 163: Baseline - SDI - Have you felt isolated?

BL - Have you felt isolated:	No.	Col %	Cum %
1 - No difficulty	225	67.6	67.6
2 - A little	67	20.1	87.7
3 - Quite a bit	21	6.3	94.0
4 - Very much	6	1.8	95.8
.a - Missing	14	4.2	100.0
Total	333	100.0	

J17 Have you had any difficulty with getting around? - *hn1_j17_dyl_mobility*

Table 164: Baseline - SDI - Have you had any difficulty with getting around?

BL - Have you had any difficulty with getting around? (e.g. transport, car parki	No.	Col %	Cum %
1 - No difficulty	241	72.4	72.4
2 - A little	58	17.4	89.8
3 - Quite a bit	17	5.1	94.9
4 - Very much	11	3.3	98.2
.a - Missing	6	1.8	100.0
Total	333	100.0	

J18 Have you had any difficulty with where you live? - *hn1_j18_dyl_dif_live*

Table 165: Baseline - SDI - Have you had any difficulty with where you live?

BL - Have you had any difficulty with where you live? (e.g. space, access, damp,	No.	Col %	Cum %
1 - No difficulty	299	89.8	89.8
2 - A little	18	5.4	95.2
3 - Quite a bit	9	2.7	97.9
4 - Very much	1	0.3	98.2
.a - Missing	6	1.8	100.0
Total	333	100.0	

J19 Have you had any difficulty in carrying out your recreational activities? - *hn1_j19_dyl_dif_recreational*

Table 166: Baseline - SDI - Have you had any difficulty in carrying out your recreational activities?

BL - Have you had any difficulty in carrying out your recreational activities? (No.	Col %	Cum %
1 - No difficulty	208	62.5	62.5
2 - A little	78	23.4	85.9
3 - Quite a bit	25	7.5	93.4
4 - Very much	18	5.4	98.8
.a - Missing	4	1.2	100.0
Total	333	100.0	

J20 Have you had any difficulty with your plans to travel or take a holiday? - *hn1_j20_dyl_dif_travel*

Table 167: Baseline - SDI - Have you had any difficulty with your plans to travel or take a holiday?

BL - Have you had any difficulty with your plans to travel or take a holiday:	No.	Col %	Cum %
1 - No difficulty	182	54.7	54.7
2 - A little	56	16.8	71.5
3 - Quite a bit	37	11.1	82.6
4 - Very much	47	14.1	96.7
.a - Missing	11	3.3	100.0
Total	333	100.0	

J21 Have you had any difficulty with any other area of your everyday life? - *hn1_j21_dyl_dif_other_area*

Table 168: Baseline - SDI - Have you had any difficulty with any other area of your everyday life?

BL - Have you had any difficulty with any other area of your everyday life:	No.	Col %	Cum %
1 - No difficulty	246	73.9	73.9
2 - A little	57	17.1	91.0
3 - Quite a bit	12	3.6	94.6
4 - Very much	9	2.7	97.3
.a - Missing	9	2.7	100.0
Total	333	100.0	

3.2.11 Your Appearance

The topics covered in the ‘Your Appearance’ questionnaire are based on the ‘Derriford Appearance Scale (DAS 24)’ questionnaire (Carr et al., 2005). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.2.3 on page 489.

K1A Is there any aspect of the appearance of your head/neck (however small) that concerns you at all? - *hn1_k1a_ya_appear_hn*

Table 169: Baseline - YA: [HN1 Quests Kq1a] Any aspect of the appearance of your head/neck that concerns you at all?

BL - Is there any aspect of the appearance head/neck that concerns you at all:	No.	Col %	Cum %
1 - Yes	51	15.3	15.3
2 - No	268	80.5	95.8
.a - Missing	14	4.2	100.0
Total	333	100.0	

K2A The aspect of my head/neck about which I am most sensitive or self-conscious is - *hn1_k2a_ya_aspect_hn*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K3A The thing I do not like about the appearance of my head/neck - *hn1_k3a_ya_hn_dont_like*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K4A If you are sensitive or concerned about any other features of - *hn1_k4a_ya_body_dont_like*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K1B How confident do you feel - *hn1_k1b_ya_confident*

Table 170: Baseline - YA: [HN1 Quests Kq1b] How confident do you feel

BL - How confident do you feel:	No.	Col %	Cum %
1 - Not at all	18	5.4	5.4
2 - Slightly	35	10.5	15.9
3 - Moderately	177	53.2	69.1
4 - Extremely	97	29.1	98.2
.a - Missing	6	1.8	100.0
Total	333	100.0	

K2B How distressed do you get when you see yourself in the mirror/window: - *hn1_k2b_ya_see_yourself_mir*

Table 171: Baseline - YA: [HN1 Quests Kq2b] How distressed do you get when you see yourself in the mirror/window:

BL - How distressed do you get when you see yourself in the mirror/window:	No.	Col %	Cum %
1 - Extremely	10	3.0	3.0
2 - Moderately	22	6.6	9.6
3 - A little	70	21.0	30.6
4 - Not at all distressed	223	67.0	97.6
.a - Missing	8	2.4	100.0
Total	333	100.0	

K3B My self-consciousness makes me irritable at home: - *hn1_k3b_ya_selfconscious*

Table 172: Baseline - YA: [HN1 Quests Kq3b] My self-consciousness makes me irritable at home

BL - My self-consciousness makes me irritable at home:	No.	Col %	Cum %
1 - N/A	171	51.4	51.4
2 - Never/Almost never	101	30.3	81.7
3 - Sometimes	46	13.8	95.5
4 - Often	4	1.2	96.7
5 - Almost always	6	1.8	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

K4B How hurt do you feel: - *hn1_k4b_ya_hurt_feel*

Table 173: Baseline - YA: [HN1 Quests Kq4b] How hurt do you feel

BL - How hurt do you feel:	No.	Col %	Cum %
1 - Extremely	20	6.0	6.0
2 - Moderately	34	10.2	16.2
3 - Slightly	79	23.7	39.9
4 - Not at all	190	57.1	97.0
.a - Missing	10	3.0	100.0
Total	333	100.0	

K5B At present my self-consciousness has an adverse effect on my work: - *hn1_k5b_ya_selfconscious_work*

Table 174: Baseline - YA: [HN1 Quests Kq5b] At present my self-consciousness has an adverse effect on my w

BL - At present my self-consciousness has an adverse effect on my work:	No.	Col %	Cum %
1 - Almost always	3	0.9	0.9
2 - Often	7	2.1	3.0
3 - Sometimes	30	9.0	12.0
4 - Never/almost never	65	19.5	31.5
5 - N/A	218	65.5	97.0
.a - Missing	10	3.0	100.0
Total	333	100.0	

K6B How distressed do you get when you go to the beach - *hn1_k6b_ya_distressed_beach*

Table 175: Baseline - YA: [HN1 Quests Kq6b] How distressed do you get when you go to the beach

BL - How distressed do you get when you go to the beach:	No.	Col %	Cum %
1 - N/A	218	65.5	65.5
2 - Not at all	83	24.9	90.4
3 - A little	13	3.9	94.3
4 - Moderately	5	1.5	95.8
5 - Extremely	4	1.2	97.0
.a - Missing	10	3.0	100.0
Total	333	100.0	

K7B Other people misjudge me because of the appearance of my head/neck: - *hn1_k7b_ya_misjudge*

Table 176: Baseline - YA: [HN1 Quests Kq7b] Other people misjudge me because of the appearance of my head/neck:

BL - Other people mis-judge me because of the appearance of my head/neck:	No.	Col %	Cum %
1 - Almost always	2	0.6	0.6
2 - Often	3	0.9	1.5
3 - Sometimes	10	3.0	4.5
4 - Never/almost never	71	21.3	25.8
5 - N/A	239	71.8	97.6
.a - Missing	8	2.4	100.0
Total	333	100.0	

K8B How feminine/masculine do you feel - *hn1_k8b_ya_fem_masc_feel***Table 177:** Baseline - YA: [HN1 Quests Kq8b] How feminine/masculine do you feel

BL - How feminine/masculine do you feel:	No.	Col %	Cum %
1 - Not at all	31	9.3	9.3
2 - Slightly	24	7.2	16.5
3 - Moderately	117	35.1	51.7
4 - Extremely	143	42.9	94.6
.a - Missing	18	5.4	100.0
Total	333	100.0	

K19B How distressed do you get when going to social events - *hn1_k19b_ya_distressed***Table 178:** Baseline - YA: [HN1 Quests Kq19b] How distressed do you get when going to social events

BL - How distressed do you get when going to social events:	No.	Col %	Cum %
1 - N/A	122	36.6	36.6
2 - Not at all	145	43.5	80.2
3 - Moderately	45	13.5	93.7
4 - A fair amount	10	3.0	96.7
5 - Extremely	4	1.2	97.9
.a - Missing	7	2.1	100.0
Total	333	100.0	

K20B How normal do you feel - *hn1_k20b_ya_normal_feel***Table 179:** Baseline - YA: [HN1 Quests Kq20b] How normal do you feel

BL - How normal do you feel:	No.	Col %	Cum %
1 - Not at all	17	5.1	5.1
2 - Slightly	19	5.7	10.8
3 - Moderately	114	34.2	45.0
4 - Extremely	175	52.6	97.6
.a - Missing	8	2.4	100.0
Total	333	100.0	

K21B At present my self-consciousness has an adverse effect on my sex life: - *hn1_k21b_ya_effect_sex_life*

Table 180: Baseline - YA: [HN1 Quests Kq21b] At present my self-consciousness has an adverse effect on my sex life:

BL - At present my self-consciousness has an adverse effect on my sex life:	No.	Col %	Cum %
1 - Almost always	13	3.9	3.9
2 - Often	9	2.7	6.6
3 - Sometimes	31	9.3	15.9
4 - Never/almost never	80	24.0	39.9
5 - N/A	190	57.1	97.0
.a - Missing	10	3.0	100.0
Total	333	100.0	

K22B Avoid going out of house - *hn1_k22b_ya_avoid_going_out*

Table 181: Baseline - YA: [HN1 Quests Kq22b] Avoid going out of house

BL - Avoid going out of house:	No.	Col %	Cum %
1 - Almost always	8	2.4	2.4
2 - Often	12	3.6	6.0
3 - Sometimes	40	12.0	18.0
4 - Never/almost never	267	80.2	98.2
.a - Missing	6	1.8	100.0
Total	333	100.0	

K23B How distressed do you get when other people make remarks about the appearance of your head/neck? - *hn1_k23b_ya_remarks_hn*

Table 182: Baseline - YA: [HN1 Quests Kq23b] How distressed do you get when other people make remarks about the appearance of your head/neck?

BL - How distressed do you get when people remark about appearance of your head/	No.	Col %	Cum %
1 - N/A	227	68.2	68.2
2 - Not at all	83	24.9	93.1
3 - Moderately	13	3.9	97.0
4 - A fair amount	4	1.2	98.2
5 - Extremely	1	0.3	98.5
.a - Missing	5	1.5	100.0
Total	333	100.0	

K24B I avoid going to pubs/restaurants - *hn1_k24b_ya_avoid_pubs*

Table 183: Baseline - YA: [HN1 Quests Kq24b] I avoid going to pubs/restaurants

BL - I avoid going to pubs/restaurants:	No.	Col %	Cum %
1 - Almost always	12	3.6	3.6
2 - Often	14	4.2	7.8
3 - Sometimes	34	10.2	18.0
4 - Never/almost never	151	45.3	63.4
5 - N/A	113	33.9	97.3
.a - Missing	9	2.7	100.0
Total	333	100.0	

K1C My feature causes me physical pain/discomfort - *hn1_k1c_ya_features*

Table 184: Baseline - YA: [HN1 Quests Kq1c] My feature causes me physical pain/discomfort

BL - My feature causes me physical pain/discomfort:	No.	Col %	Cum %
1 - Never/almost never	220	66.1	66.1
2 - Sometimes	58	17.4	83.5
3 - Often	21	6.3	89.8
4 - Almost always	14	4.2	94.0
.a - Missing	20	6.0	100.0
Total	333	100.0	

K2C My feature limits my physical ability to do the things I want to do: - *hn1_k2c_ya_physical_ability*

Table 185: Baseline - YA: [HN1 Quests Kq2c] My feature limits my physical ability to do the things I want to do:

BL - My feature limits my physical ability to do the things I want to do:	No.	Col %	Cum %
1 - Almost always	13	3.9	3.9
2 - Often	10	3.0	6.9
3 - Sometimes	45	13.5	20.4
4 - Never/almost never	239	71.8	92.2
.a - Missing	26	7.8	100.0
Total	333	100.0	

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? - *hn1_k3c_ya_disfigurement*

Table 186: Baseline - YA: [HN1 Quests Kq3c] To what extent is any disfigurement or change to your appearance as a result of your cancer or its treatment noticeable to other people?

BL - To what extent is any disfigurement or change to your appearance as a result	No.	Col %	Cum %
1 - Not at all noticable	197	59.2	59.2
2 - 2	35	10.5	69.7
3 - 3	16	4.8	74.5
4 - Moderately noticable	36	10.8	85.3
5 - 5	10	3.0	88.3
6 - 6	3	0.9	89.2
7 - Extremely noticable	3	0.9	90.1
.a - Missing	33	9.9	100.0
Total	333	100.0	

K4C How much will your treatment change the way you look - *hn1_k5c_ya_treatment*

Table 187: Baseline - YA: [HN1 Quests Kq5c] How much will your treatment change the way you look

BL - How much will your treatment change the way you look	No.	Col %	Cum %
1 - Not at all	131	39.3	39.3
2 - 2	70	21.0	60.4
3 - 3	56	16.8	77.2
4 - 4	10	3.0	80.2
5 - Very much	16	4.8	85.0
.a - Missing	50	15.0	100.0
Total	333	100.0	

K6C How much does this bother you - *hn1_k6c_ya_bother_you*

Table 188: Baseline - YA: [HN1 Quests Kq6c] How much does this bother you

BL - How much does this bother you	No.	Col %	Cum %
1 - Not at all	165	49.5	49.5
2 - 2	52	15.6	65.2
3 - 3	32	9.6	74.8
4 - 4	12	3.6	78.4
5 - Very much so	24	7.2	85.6
.a - Missing	48	14.4	100.0
Total	333	100.0	

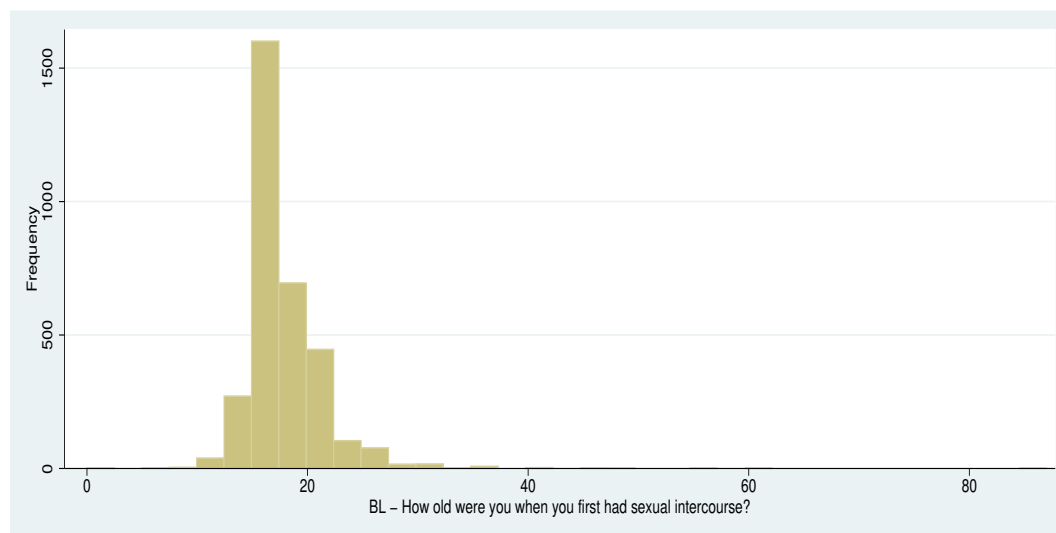
3.2.12 Sexual Health

The topics covered in the ‘Sexual Health’ questionnaire are based on the ‘Sexual History’ questionnaire (Castellsague et al., 2002). Further details of the questionnaire used can be found in Appendix B.2.4 on page 501.

M1 How old were you when you first had sexual intercourse? - *hn1_m1_sh_age_sex*

- Descriptives:
 - Total valid responses = 3292, number of missing values or data check errors = 114

Figure 38: Baseline - SH: How old were you when you first had sexual intercourse?

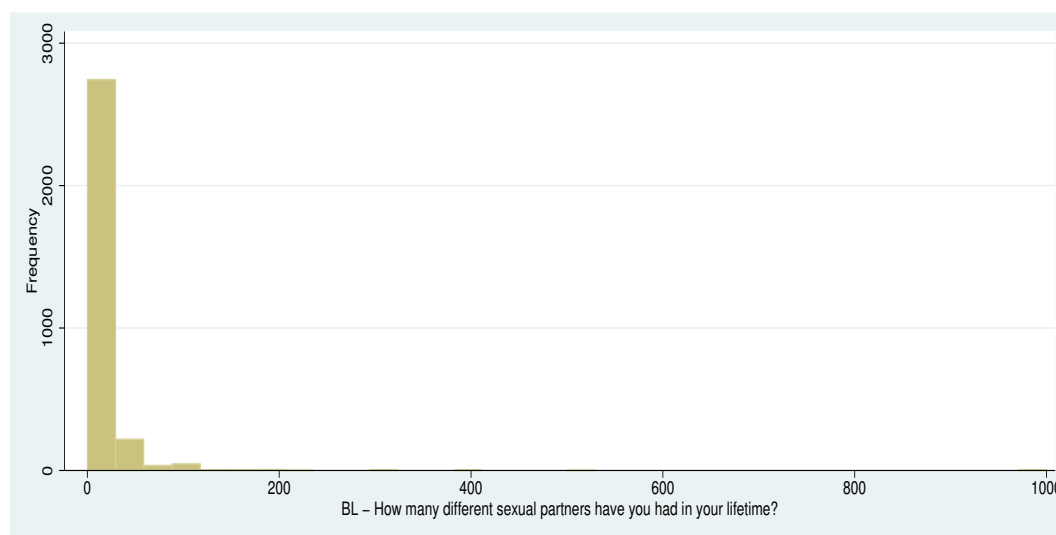


M2 How many different sexual partners have you had in your lifetime? - *hn1_m2_sh_sex_partners*

- Descriptives:

- Total valid responses = 3067, number of missing values or data check errors = 339

Figure 39: Baseline - SH: How many different sexual partners have you had in your lifetime?



M3A Have you ever performed oral sex on a partner? - *hn1_m3a_sh_oral_sex*

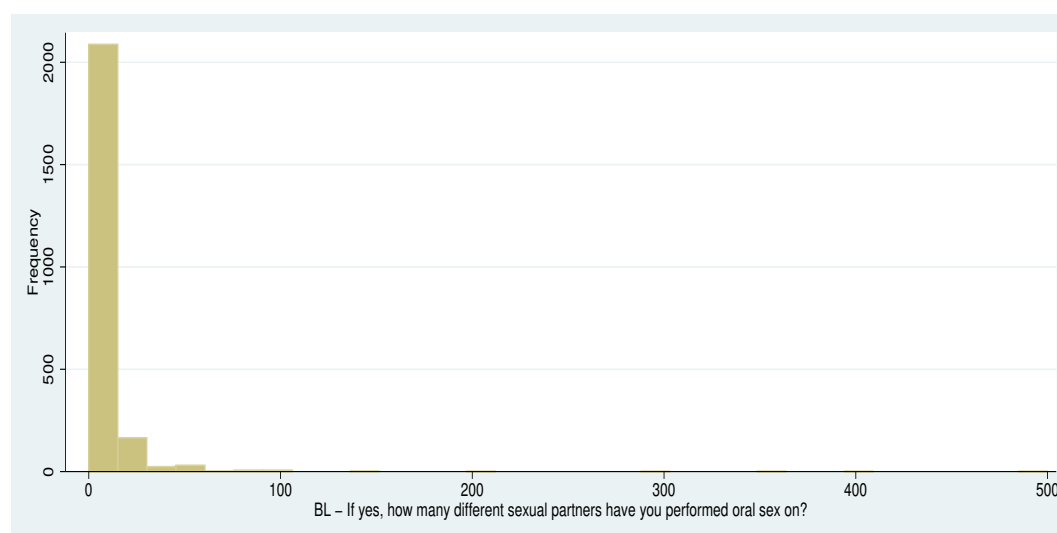
Table 189: Baseline - SH - Have you ever performed oral sex on a partner?

BL - Have you ever performed oral sex on a partner?	No.	Col %	Cum %
1 - Yes	2715	79.7	79.7
2 - No	610	17.9	97.6
.a - Missing	81	2.4	100.0
Total	3406	100.0	

M3B If yes, how many different sexual partners have you performed oral sex on? - *hn1_m3b_sh_no_oral_sex*

- Descriptives:
 - Total valid responses = 2331, number of missing values or data check errors = 1075

Figure 40: Baseline - SH: If yes, how many different sexual partners have you performed oral sex on?



M4 Have you ever had sex with a same sex partner? - *hn1_m4a_sh_same_sex*

Table 190: Baseline - SH - Have you ever had sex with a same sex partner?

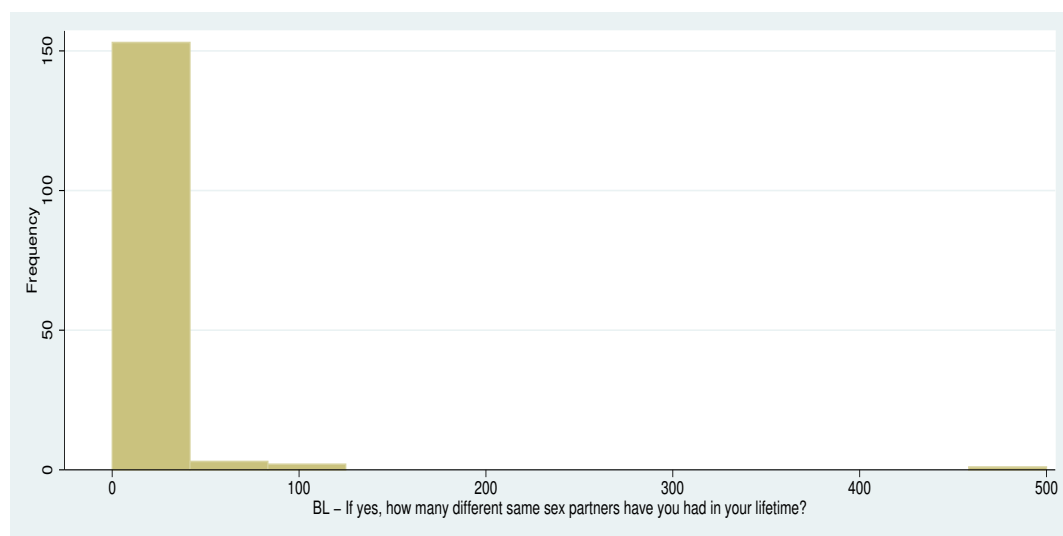
BL - Have you ever had sex with a same sex partner?	No.	Col %	Cum %
1 - Yes	158	4.6	4.6
2 - No	3076	90.3	95.0
3 - Do not know	19	0.6	95.5
.a - Missing	153	4.5	100.0
Total	3406	100.0	

M4B If yes, how many different same sex partners have you had in your lifetime? - *hn1_m4b_sh_no_same_sex*

- Descriptives:

- Total valid responses = 159, number of missing values or data check errors = 3247

Figure 41: Baseline - SH: If yes, how many different same sex partners have you had in your lifetime?



M5 Have you ever been diagnosed or treated for genital warts? - *hn1_m5_sh_diag_gen_warts*

Table 191: Baseline - SH - Have you ever been diagnosed or treated for genital warts?

BL - Have you ever been diagnosed or treated for genital warts?	No.	Col %	Cum %
1 - Yes	200	5.9	5.9
2 - No	3026	88.8	94.7
3 - Do not know	40	1.2	95.9
.a - Missing	140	4.1	100.0
Total	3406	100.0	

M6 Have you ever had a sexual partner who had genital warts? - *hn1_m6_sh_partner_gen_warts*

Table 192: Baseline - SH - Have you ever had a sexual partner who had genital warts?

BL - Have you ever had a sexual partner who had genital warts?	No.	Col %	Cum %
1 - Yes	161	4.7	4.7
2 - No	2570	75.5	80.2
3 - Do not know	603	17.7	97.9
.a - Missing	72	2.1	100.0
Total	3406	100.0	

M7A If female, have you ever had an abnormal pap smear? - *hn1_m7a_sh_fem_pap_smear*

Table 193: Baseline - SH - If female, have you ever had an abnormal pap smear?

BL - If female, have you ever had an abnormal pap smear?	No.	Col %	Cum %
1 - Yes	185	19.1	19.1
2 - No	696	71.8	90.9
3 - Do not know	54	5.6	96.5
.a - Missing	34	3.5	100.0
Total	969	100.0	

M7B If male, have any of your sexual partners ever had an abnormal pap smear? - *hn1_m7b_sh_male_pap_smear*

Table 194: Baseline - SH - If male, have any of your sexual partners ever had an abnormal pap smear?

BL - If male, have any of your sexual partners ever had an abnormal pap smear?	No.	Col %	Cum %
1 - Yes	137	5.6	5.6
2 - No	1211	49.7	55.3
3 - Do not know	976	40.0	95.4
.a - Missing	113	4.6	100.0
Total	2437	100.0	

M8A If female, have you ever been diagnosed with cervical cancer? - *hn1_m8a_sh_fem_cerv_canc*

Table 195: Baseline - SH - If female, have you ever been diagnosed with cervical cancer?

BL - If female, have you ever been diagnosed with cervical cancer?	No.	Col %	Cum %
1 - Yes	40	4.1	4.1
2 - No	882	91.0	95.1
3 - Do not know	6	0.6	95.8
.a - Missing	41	4.2	100.0
Total	969	100.0	

M8B If male, have any of your sexual partners ever been diagnosed with cervical cancer? - *hn1_m8b_sh_male_cerv_canc*

Table 196: Baseline - SH - If male, have any of your sexual partners ever been diagnosed with cervical cancer?

BL - If male, have any of your sexual partners ever been diagnosed with cervical	No.	Col %	Cum %
1 - Yes	97	4.0	4.0
2 - No	1566	64.3	68.2
3 - Do not know	681	27.9	96.2
.a - Missing	93	3.8	100.0
Total	2437	100.0	

M9 If male, are you circumcised? - *hn1_m9_sh_circumcised*

Table 197: Baseline - SH - If male, are you circumcised?

BL - If male, are you circumcised?	No.	Col %	Cum %
1 - Yes	606	24.9	24.9
2 - No	1749	71.8	96.6
3 - Do not know	19	0.8	97.4
.a - Missing	63	2.6	100.0
Total	2437	100.0	

4 Stage 2 - 4-Months

4.1 Data Capture Form

4.1.1 Section A - Basic Data

In order to protect the confidentiality of participants the following date variables are not available. Variables have been derived (see the appropriate ‘Derived variables’ sections) which describe participants’ age at events. These variables can be used to define timelines for participants.

1 Date of data collection (*hn2_na1_cb_date*) - please use ‘Days from consent to 4M DCF data collection’ (*hn2_dv_dcf_age*)

5-A TNM date (*hn2_nb5a_cb_tnm_date*) - please use ‘Days from consent to definitive TNM staging’ (*hn2_dv_tnm_age*)

4.1.2 Section B - Treatment**1a Actual cancer plan intent 1***hn2_nbl_cb_plan_intent_1*

- Data check
- Used to derive
- Descriptives

Table 198: 4-months - Actual cancer plan intent 1

4M - Plan Intent 1:	No.	Col %	Cum %
1 - Curative	5166	96.4	96.4
2 - Palliative	152	2.8	99.3
3 - Supportive	35	0.7	99.9
4 - No Specific anti-cancer	3	0.1	100.0
.a - Missing	1	0.0	100.0
Total	5357	100.0	

Notes:

1b Actual cancer plan intent 2*hn2_nb1_cb_plan_intent_2*

- Data check
- Used to derive
- Descriptives

Table 199: 4-months - Actual cancer plan intent 2

4M - Plan Intent 2 (4M and 12M only):	No.	Col %	Cum %
1 - Curative	2	0.0	0.0
2 - Palliative	27	0.5	0.5
3 - Supportive	17	0.3	0.9
5 - N/A	5311	99.1	100.0
Total	5357	100.0	

Notes:

1c Actual cancer plan intent 3*hn2_nb1_cb_plan_intent_3*

- Data check
- Used to derive
- Descriptives

Table 200: 4-months - Actual cancer plan intent 3

4M - Plan Intent 3 (4M and 12M only):	No.	Col %	Cum %
1 - Curative	1	0.0	0.0
2 - Palliative	1	0.0	0.0
5 - N/A	5355	100.0	100.0
Total	5357	100.0	

Notes:

2 Actual cancer treatment type*hn2_nb2_cb*

- **Data check**
- **Used to derive**
 - Actual treatment - grouped (hn2_dv_treatment_grp)
- **Descriptives**

Table 201: 4-months - Actual cancer treatment type

	No.	Col %
4M - Surgery(Primary Site):		
1 - Yes	2315	100.0
Total	2315	100.0
4M - Surgery(Neck):		
1 - Yes	1665	100.0
Total	1665	100.0
4M - Teletherapy:		
1 - Yes	1877	100.0
Total	1877	100.0
4M - Chemotherapy:		
1 - Yes	620	100.0
Total	620	100.0
4M - Hormone therapy:		
1 - Yes	27	100.0
Total	27	100.0
4M - Specialist Paliative:		
1 - Yes	53	100.0
Total	53	100.0
4M - Brachytherapy:		
1 - Yes	89	100.0
Total	89	100.0
4M - Biological:		
1 - Yes	107	100.0
Total	107	100.0
4M - Other:		
1 - Yes	211	100.0
Total	211	100.0
4M - Active Monitoring:		
1 - Yes	653	100.0
Total	653	100.0
4M - Combined chemoradiotherapy:		
1 - Yes	2008	100.0
Total	2008	100.0
4M - Reconstruction with free flap:		
1 - Yes	671	100.0
Total	671	100.0
4M - Laser surgery:		
1 - Yes	209	100.0
Total	209	100.0

Notes:

3 Treatment type sequence*hn2_nb3_cb_sequence*

- **Data check**
 - **Used to derive**
 - **Descriptives:**
-

Notes: – Data for this field are currently undergoing further processing. A cleaned version of this variable will be available in a future data release.

4 Co-morbidity*hn2_nb4_cb_comorb_index*

- **Data check**
- **Used to derive**
- **Descriptives**

Table 202: 4-months - Co-morbidity

4M - Co-morb index:	No.	Col %	Cum %
1 - No co-morbidity	2186	40.8	40.8
2 - Mild discompensation	1680	31.4	72.2
3 - Moderate discompensation	932	17.4	89.6
4 - Severe discompensation	293	5.5	95.0
5 - Unknown	214	4.0	99.0
.a - Missing	52	1.0	100.0
Total	5357	100.0	

Notes:

5 TNM Category

hn2_TNM_stage

- **Data check**
- **Used to derive**
 - Final clinical staging - *hn2_TNM_stage*
 - Simplified - Final clinical staging - *hn2_TNM_stage2*
- **Descriptives**

Table 203: 4-months - T, N & M codes

hn2_nb5b_cb_t_New	No.	Col %	Cum %
1	1235	23.1	23.1
1a	178	3.3	26.4
1b	115	2.1	28.5
2	1741	32.5	61.0
2a	8	0.1	61.2
2b	13	0.2	61.4
3	769	14.4	75.8
3a	1	0.0	75.8
4	620	11.6	87.4
4a	439	8.2	95.6
4b	73	1.4	96.9
x	154	2.9	99.8
	11	0.2	100.0
Total	5357	100.0	

hn2_nb5c_cb_n_New	No.	Col %	Cum %
0	2738	51.1	51.1
1	583	10.9	62.0
2	1947	36.3	98.3
3	79	1.5	99.8
x	1	0.0	99.8
	9	0.2	100.0
Total	5357	100.0	

hn2_nb5d_cb_m_New	No.	Col %	Cum %
0	5263	98.2	98.2
1	63	1.2	99.4
x	2	0.0	99.5
	29	0.5	100.0
Total	5357	100.0	

Notes:

5b Pathological tumour staging

- **Data check**
 - **Used to derive**
 - **Descriptives:**
-

Notes: – This data is currently being cleaned and will be available in future versions of the data manual.

11 Was radiotherapy completed?*hn2_nb11_cb_radiotherapy*

- Data check
- Used to derive
- Descriptives

Table 204: 4-months - Was radiotherapy completed?

4M - Was the initial/prescribed course of radioth treatmt completed:	No.	Col %	Cum %
1 - Yes	3633	67.8	67.8
2 - No	80	1.5	69.3
3 - Ongoing	249	4.6	74.0
4 - Not Applicable	1382	25.8	99.8
.a - Missing	13	0.2	100.0
Total	5357	100.0	

Notes:

11a Radiotherapy incomplete reason*hn2_nb11a_cb_radio_incomp*

- Data check
- Used to derive
- Descriptives

Table 205: 4-months - Radiotherapy incomplete - reason

4M - Radioth not completed reason:	No.	Col %	Cum %
1 - Toxicity/side effects	29	0.5	0.5
2 - Altered treatment plan	10	0.2	0.7
3 - Patient choice	18	0.3	1.1
4 - Other	22	0.4	1.5
.a - Missing	5278	98.5	100.0
Total	5357	100.0	

Notes:

12 Was chemotherapy completed?*hn2_nb12_cb_chemotherapy*

- Data check
- Used to derive
- Descriptives

Table 206: 4-months - Was chemotherapy completed

4M - Was the initial/prescribed course of chemotherapy treatment completed:	No.	Col %	Cum %
1 - Yes	1711	31.9	31.9
2 - No	304	5.7	37.6
3 - Ongoing	145	2.7	40.3
4 - Not Applicable	3183	59.4	99.7
.a - Missing	14	0.3	100.0
Total	5357	100.0	

Notes:

12a Chemotherapy incomplete reason*hn2_nb12a_cb_chemo_incomp*

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 207: 4-months - Chemotherapy incomplete - reason

4M - Radioth not completed reason:	No.	Col %	Cum %
1 - Toxicity/side effects	235	4.4	4.4
2 - Altered treatment plan	17	0.3	4.7
3 - Patient choice	16	0.3	5.0
4 - Other	37	0.7	5.7
.a - Missing	5052	94.3	100.0
Total	5357	100.0	

Notes:

13 PEG*hn2_nb13_cb_peg*

- **Data check**
- **Used to derive**
- **Descriptives**

Table 208: 4-months - PEG

4M - Does the patient have peg:	No.	Col %	Cum %
1 - Yes	1684	31.4	31.4
2 - No	3632	67.8	99.2
.a - Missing	41	0.8	100.0
Total	5357	100.0	

Notes:

14 How much feeding through PEG*hn2_nb14_cb_feeding_peg*

- **Data check**
 - If ‘PEG’ = yes & ‘How much feeding through PEG’ = missing
- **Used to derive**
- **Descriptives**

Table 209: 4-months - How much feeding through PEG

4M - Approximately how much feeding is through peg:	No.	Col %	Cum %
1 - None	268	5.0	5.0
2 - Less than 20%	134	2.5	7.5
3 - 20-80%	461	8.6	16.1
4 - Greater than 80%	667	12.5	28.6
.a - Missing	3827	71.4	100.0
Total	5357	100.0	

Notes:

15 Tracheostomy*hn2_nb15_cb_tracheostomy*

- **Data check**
- **Used to derive**
- **Descriptives**

Table 210: 4-months - Tracheostomy

4M - Does the patient have a tracheostomy:	No.	Col %	Cum %
1 - Yes	220	4.1	4.1
2 - No	5088	95.0	99.1
.a - Missing	49	0.9	100.0
Total	5357	100.0	

Notes:

16a Tumour recurrence*hn2_nb16a_cb_recurrence*

- Data check
- Used to derive
- Descriptives

Table 211: 4-months - Tumour recurrence

4M - Has there been tumour recurrence:	No.	Col %	Cum %
1 - Yes	79	1.5	1.5
2 - No	4737	88.4	89.9
3 - NA	411	7.7	97.6
.a - Missing	130	2.4	100.0
Total	5357	100.0	

Notes:

16 Tumour recurrence stage -• **Data check**

– If ‘Tumour recurrence’ = yes & ‘Tumour recurrence stage’ = missing

• **Used to derive**• **Descriptives****Table 212:** 4-months - Recurrence T, N & M codes

4M - T	No.	Col %	Cum %
,	1	0.0	0.0
0	3	0.1	0.1
1	5	0.1	0.2
2	6	0.1	0.3
3	1	0.0	0.3
4	9	0.2	0.5
4a	3	0.1	0.5
x	2	0.0	0.6
	5327	99.4	100.0
Total	5357	100.0	

4M - N	No.	Col %	Cum %
0	9	0.2	0.2
1	2	0.0	0.2
2	5	0.1	0.3
2b	7	0.1	0.4
2c	4	0.1	0.5
3	2	0.0	0.5
x	2	0.0	0.6
	5326	99.4	100.0
Total	5357	100.0	

4M - M	No.	Col %	Cum %
0	17	0.3	0.3
1	13	0.2	0.6
2	1	0.0	0.6
x	1	0.0	0.6
	5325	99.4	100.0
Total	5357	100.0	

Notes:

4.1.3 Section C - Other**1 Patient trial status***hn2_nc1_cb_pts_trial_status***Table 213:** 4-months - Patient trial status

4M - Patient trial status:	No.	Col %	Cum %
1 - Eligible, entered	493	9.2	9.2
2 - Eligible, declined	61	1.1	10.3
3 - Eligible, not approached	127	2.4	12.7
4 - Ineligible	949	17.7	30.4
5 - Not applicable	3644	68.0	98.5
.a - Missing	83	1.5	100.0
Total	5357	100.0	

Notes:

2 Comments*hn2_nc2_cb_comments*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

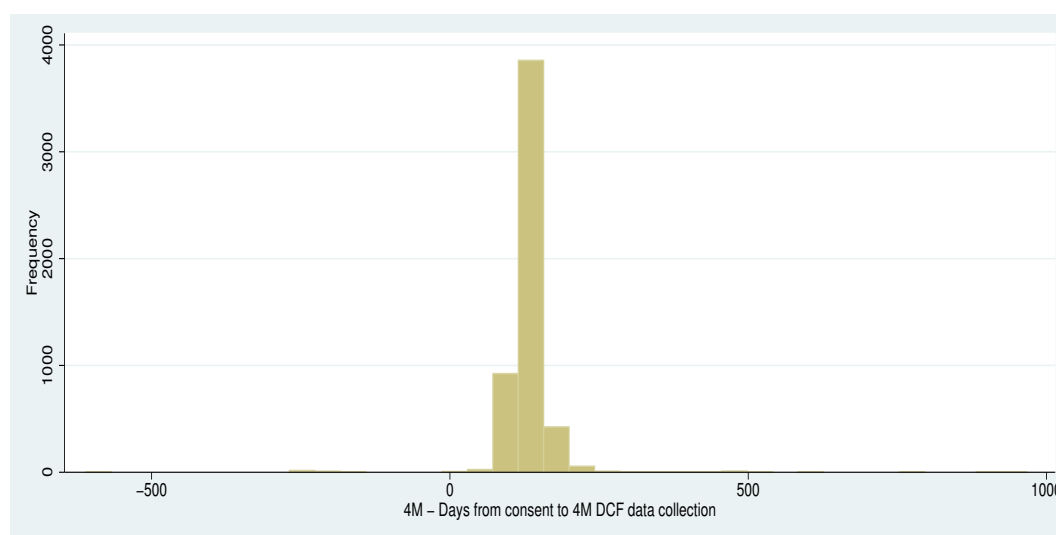
4.1.4 Derived variables

Variables derived from the 4-month Data Capture Forms.

1. Days from consent to 4M DCF data collection

- *Date of 4M DCF data collection (hn2_na1_cb_date) - Date of birth (hn1_na2_cb_dob)*
- Stata code to derive variable:
 - `gen hn2_dv_dcf_age = hn2_na1_cb_date - hn1_na2_cb_dob`
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 5357, number of missing values or data check errors = 0

Figure 42: Days from consent to 4M DCF data collection

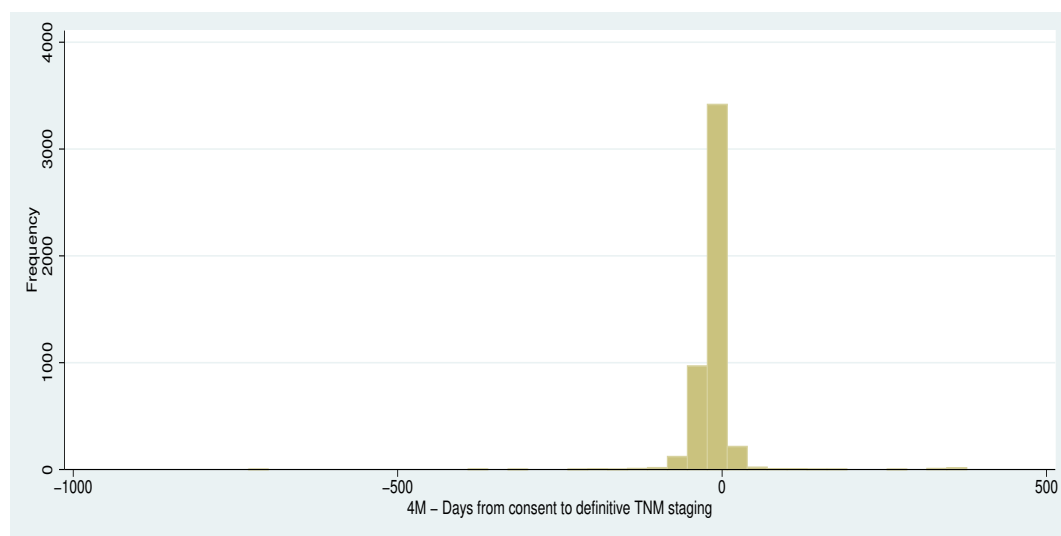


Notes:

2. Days from consent to definitive TNM staging

- *Date of definitive TNM staging (hn2_nb5a_cb_tnm_date) - Date of birth (hn1_na2_cb_dob)*
- Stata code to derive variable:
 - `gen hn2_dv_tnm_age = hn2_nb5a_cb_tnm_date - hn1_na2_cb_dob`
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 4821, number of missing values or data check errors = 536

Figure 43: Days from consent to definitive TNM staging

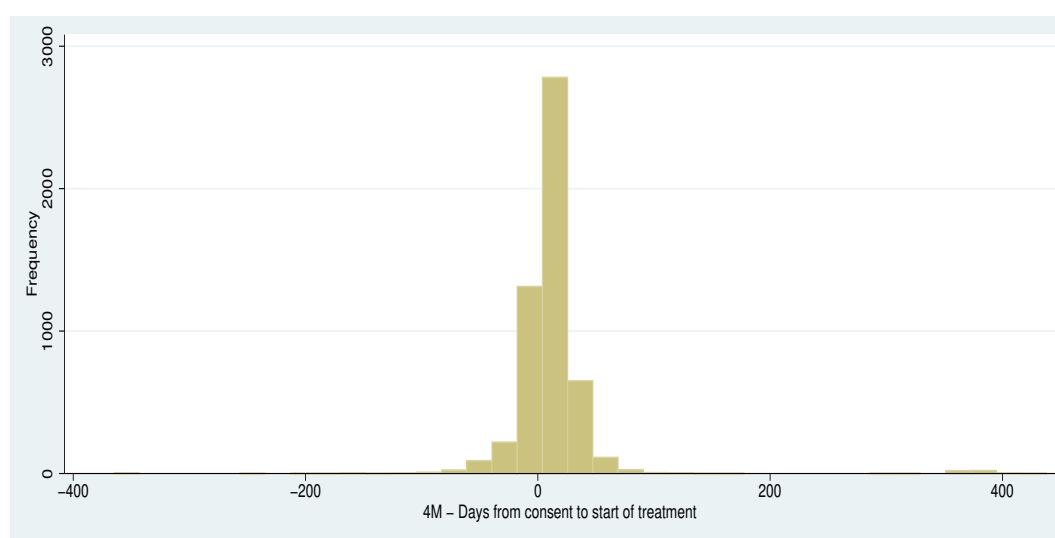


Notes:

3. Days from consent to start of treatment

- Date of start of treatment (*hn2_nb10_cb_start_date*) - Date of birth (*hn1_na2_cb_dob*)
- Stata code to derive variable:
 - `gen hn2_dv_start_age = hn2_nb10_cb_start_date - hn1_na2_cb_dob`
- Used to derive
- Descriptives:
 - Total valid responses = 5298, number of missing values or data check errors = 59

Figure 44: Days from consent to start of treatment

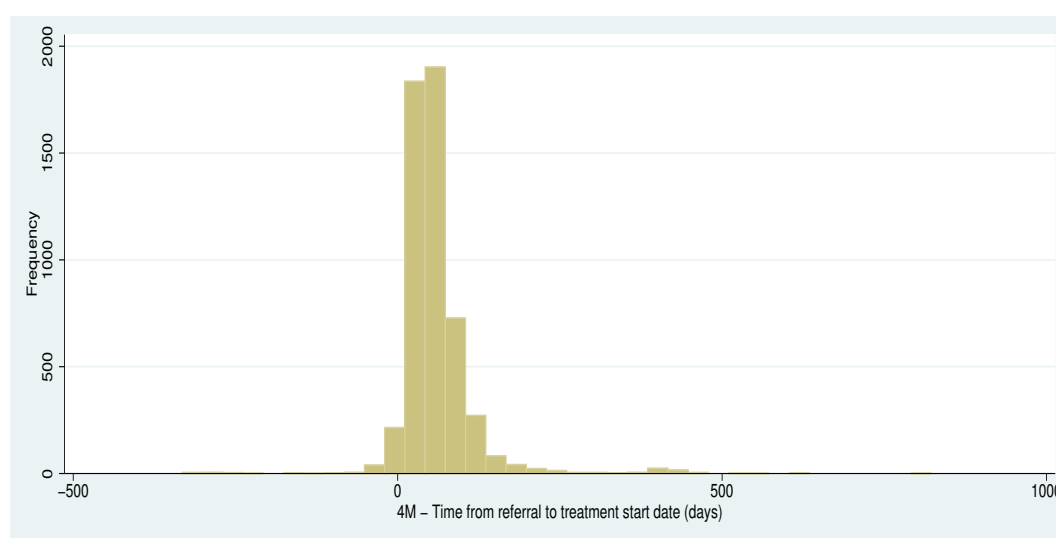


Notes:

4. Time from referral to treatment start date

- Date of treatment start (*hn2_nb10_cb_start_date*) - Date of Referral (*hn1_na3_cb_dor*)
- Stata code to derive variable:
 - `gen hn2_dv_treat_ref = hn2_nb10_cb_start_date - hn1_na3_cb_dor`
- Used to derive
- Descriptives:
 - Total valid responses = 5253, number of missing values or data check errors = 104

Figure 45: Time from referral to treatment start date



Notes:

5. Final clinical staging

hn2_TNM_stage

- Using TNM categories

Table 214: 4-months - Final clinical staging

4M - TNM staging	No.	Col %	Cum %
1 - I	1173	21.9	21.9
2 - II	867	16.2	38.1
3 - IIa	12	0.2	38.3
4 - IIb	19	0.4	38.7
5 - III	684	12.8	51.4
6 - IVa	2213	41.3	92.7
7 - IVb	123	2.3	95.0
8 - IVc	55	1.0	96.1
.e - Incomplete T and/or N and/or M codes	31	0.6	96.6
.f - TNM combination unacceptable	28	0.5	97.2
.g - Other	152	2.8	100.0
Total	5357	100.0	

- Notes:**
- Tumour staging was derived using the 'TNM staging of head and neck cancer and neck dissection classification' Deschler and Day (2008).
 - The 'Other' category refers to patients with either an unknown primary tumour site, no valid ICD code or with a valid ICD code which is not currently allocated to a tumour site group. Refer to *hn1_ICD_group* for more details.

6. Simplified - Final clinical staging

hn2_TNM_stage2

- Using TNM categories

Table 215: 4-months - Simplified - Final clinical staging

4M - Simplified TNM staging	No.	Col %	Cum %
1 - I	1180	22.0	22.0
2 - II	902	16.8	38.9
3 - III	706	13.2	52.0
4 - IV	2402	44.8	96.9
.e - Incomplete T and/or N and/or M codes	10	0.2	97.1
.f - TNM combination unacceptable	5	0.1	97.2
.g - Other	152	2.8	100.0
Total	5357	100.0	

- Notes:**
- The simplified tumour staging was derived using a modified version of the 'TNM staging of head and neck cancer and neck dissection classification' Deschler and Day (2008). See Appendix B for details.
 - The 'Other' category refers to patients with either an unknown primary tumour site, no valid ICD code or with a valid ICD code which is not currently allocated to a tumour site group. Refer to *hn1_ICD_group* for more details.

7. Pathological TNM staging

- Using pT, pN and pM data
- Note: This variable is currently being derived and will be updated in a future release of the Data Manual.

4.2 Questionnaires

4.2.1 About You

The topics covered in the 'About You' questionnaire are:

1. Education and occupation - (Lagiou et al., 2009)
2. Income - (Benzeval et al., 2009)
3. EQ5D - (Brooks et al., 2003)
4. Smoking and alcohol - (The Million Women Study Collaborative Group, 1999; Sitas et al., 2013)

Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

In order to protect the confidentiality of participants the following date variables are not available. Variables have been derived (see the appropriate ‘Derived variables’ sections) which describe participants’ age at events. These variables can be used to define timelines for participants.

A1 Date of completion (*hn2_a1_ay_date*) - Please use ‘Age at completion of 4M AY (days)’ (*hn2_dv_ay_age*)

A2 Date of birth (*hn2_a2_ay_dob*) - Please use ‘Age at completion of 4M AY (days)’ (*hn2_dv_ay_age*)

A4a Self-reported weight (kg)*hn2_a4a_ay_kg_weight***A4b1 Self-reported weight (stone)***hn2_a4b1_ay_stone_weight***A4b2 Self-reported weight (lbs)***hn2_a4b2_ay_lbs_weight*

Notes: • These variables have not been documented. Please refer to the derived variable which combines these variables in a single variable for 'weight' - *hn2_dv_weight_kg*.

A5 Marital status*hn2_a5_ay_marital_status*

- Categories
 - 1 *Single*
 - 2 *Widowed*
 - 3 *Separated*
 - 4 *Married*
 - 5 *Divorced*
 - 6 *Living with a partner*
- Quality control
- Used to derive

Table 216: 4-months - AY: Marital status

4M - Are you currently:	No.	Col %	Cum %
1 - Single	374	11.3	11.3
2 - Widowed	252	7.6	18.9
3 - Separated	76	2.3	21.2
4 - Married	1909	57.7	78.9
5 - Divorced	338	10.2	89.1
6 - Living with a partner	331	10.0	99.1
.a - Missing	29	0.9	100.0
Total	3309	100.0	

Notes:

A8a Tobacco 4/12 mnth*hn2_a8_ay_tobacco4mnth*

- Quality control
- Used to derive:
- Descriptives:

Table 217: 4-months - AY: [HN1 Quests Aq8a] Tobacco 4/12 mnth

4M - Tobacco 4 mnth	No.	Col %	Cum %
1 - Current User	332	10.0	10.0
2 - Former or Never	2164	65.4	75.4
.a - Missing	813	24.6	100.0
Total	3309	100.0	

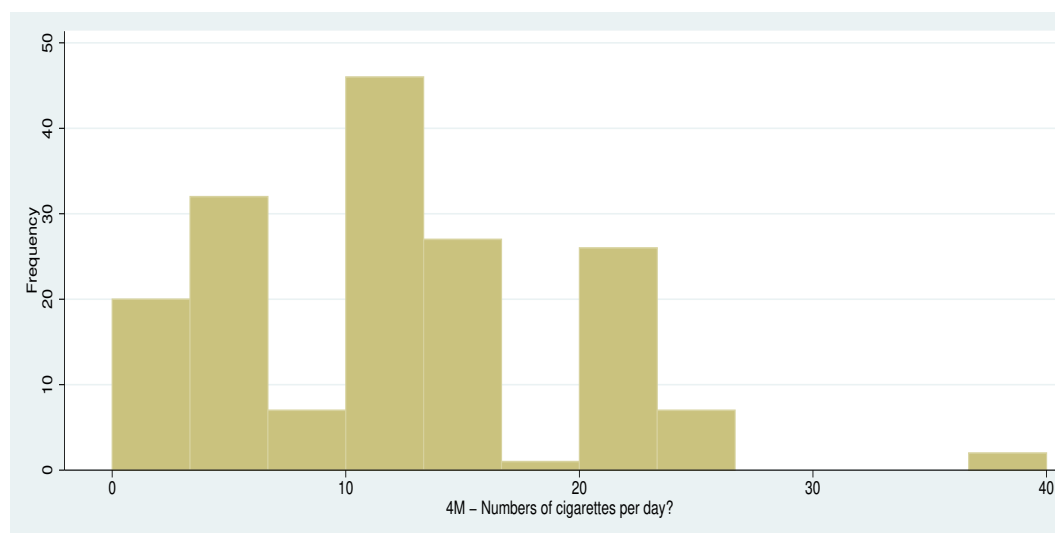
Notes:

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

a) Numbers of cigarettes per day? - *hn2_a11a_ay_cigs_pd*

– Total valid responses = 168, number of missing values or data check errors = 164

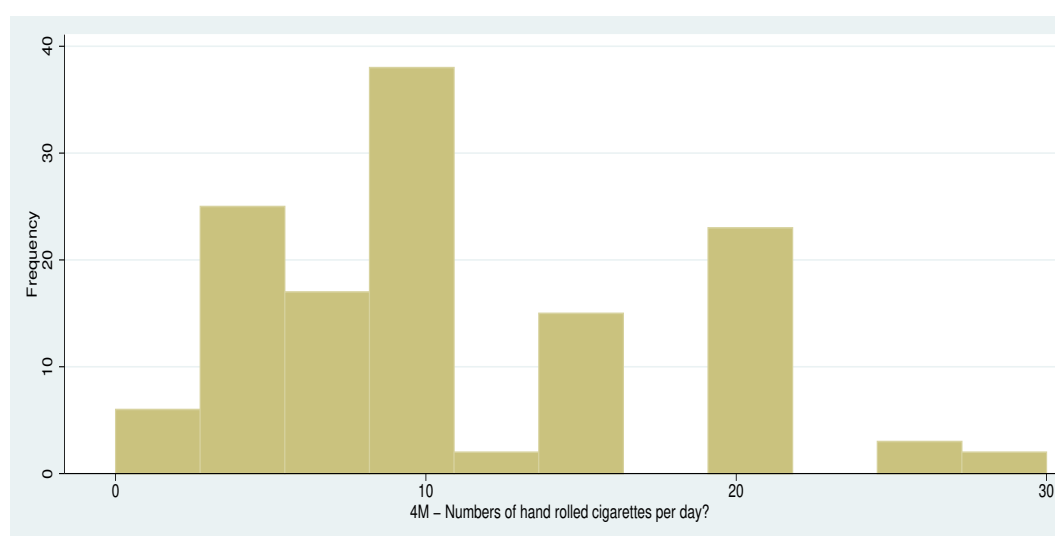
Figure 46: 4-months - AY: Number of cigarettes per day?



b) Numbers of hand rolled cigarettes per day? - *hn2_a11b_ay_hand_pd*

– Total valid responses = 131, number of missing values or data check errors = 201

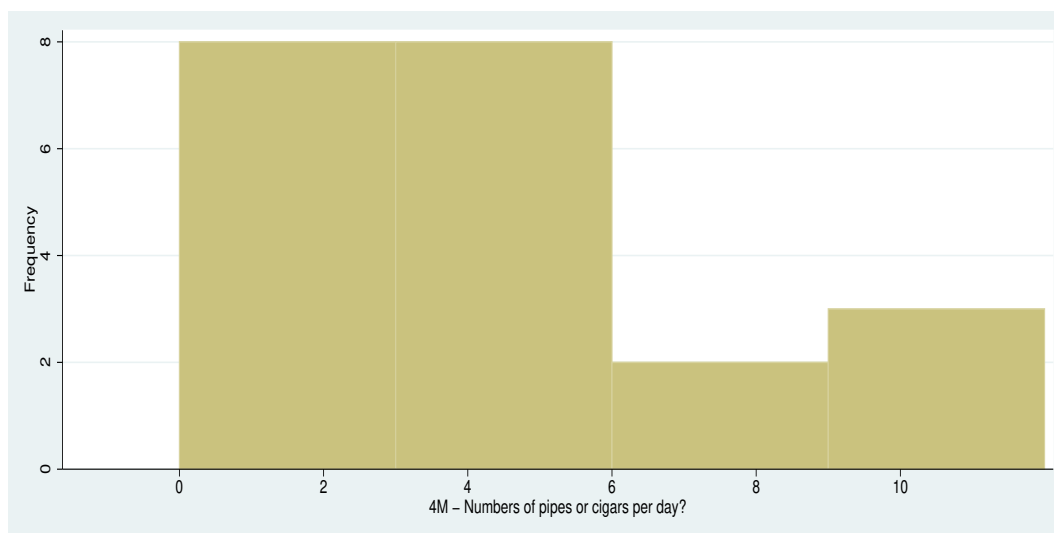
Figure 47: 4-months - AY: Number of hand rolled cigarettes per day?



c) Numbers of pipes or cigars per day? - *hn2_allc_ay_pipe_pd*

– Total valid responses = 21, number of missing values or data check errors = 311

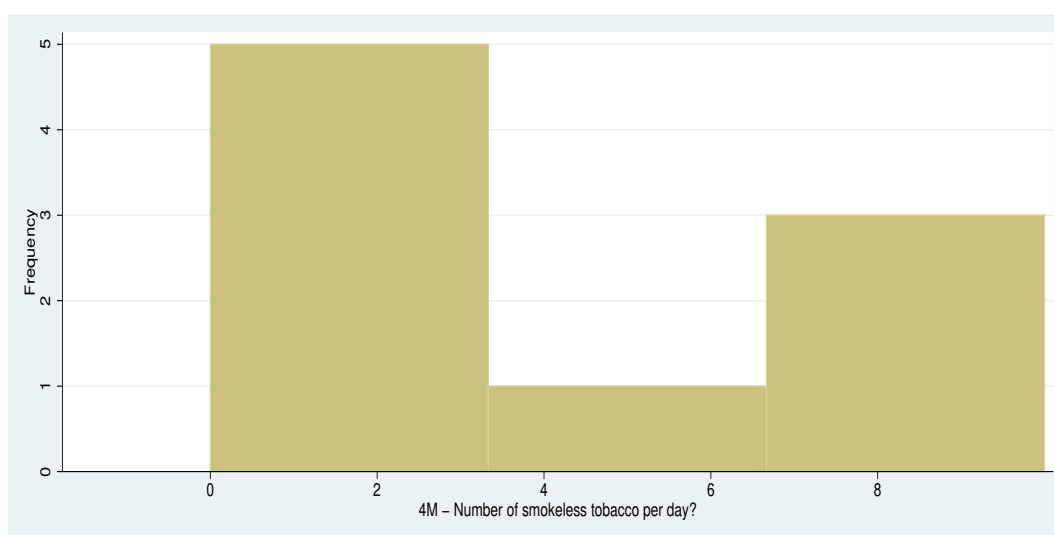
Figure 48: 4-months - AY: Number of pipes or cigars per day?



d) Numbers of smokeless tobacco per day? - *hn2_alld_ay_smokeless_pd*

– Total valid responses = 9, number of missing values or data check errors = 323

Figure 49: 4-months - AY: Number of smokeless tobacco per day?



Notes:

A12 What brand of cigarettes/tobacco do you/did you normally smoke?*hn2_a12_ay_brand_smoke*

Notes: • This is a free text field and will not be documented. Data for this variable are available through a standard data request.

A13a In a typical week how many days do you drink alcohol?*hn2_a13a_ay_drink_days*

- Quality control
- Used to derive

Table 218: 4-months - AY: In a typical week how many days do you drink alcohol?

4M - In a typical week how many days do you drink alcohol?	No.	Col %	Cum %
0	257	7.8	7.8
1	292	8.8	16.6
2	343	10.4	27.0
3	236	7.1	34.1
4	153	4.6	38.7
5	174	5.3	44.0
6	46	1.4	45.4
7	299	9.0	54.4
.a	1509	45.6	100.0
Total	3309	100.0	

A13b 'None' ticked - *hn2_a13b_ay_drink_days***Table 219:** 4-months - AY: None ticked

4M - If none, tick the box and go to question A17	No.	Col %	Cum %
1 - Ticked	1317	39.8	39.8
.a - Missing	1992	60.2	100.0
Total	3309	100.0	

Notes:

A15 About how many bottles of wine, spirits and pints of beers did you drink on average each week?**Table 220:** 4-months - AY: About how many bottles of wine, spirits and pints of beers did you drink on average each week?a) Bottles of wine - *hn2_a15a_ay_wine_pw*

4M - About how many bottles of wine,did you drink on average each week?	No.	Col %	Cum %
1 - None	357	17.9	17.9
2 - Less than 1	324	16.3	34.2
3 - 1	209	10.5	44.7
4 - 2-3	220	11.0	55.7
5 - 4-6	56	2.8	58.5
6 - 7-10	17	0.9	59.4
7 - 11 or more	2	0.1	59.5
.a - Missing	807	40.5	100.0
Total	1992	100.0	

b) Bottles of Spirits - *hn2_a15b_ay_spirits_pw*

4M - About how many bottles of spirits,did you drink on average each week?	No.	Col %	Cum %
1 - None	565	28.4	28.4
2 - Less than 1	218	10.9	39.3
3 - 1	58	2.9	42.2
4 - 2-3	31	1.6	43.8
5 - 4-6	1	0.1	43.8
.a - Missing	1119	56.2	100.0
Total	1992	100.0	

c) Pints of beer/lager/cider - *hn2_a15c_ay_pints_pw*

4M - About how many pints of beers, did you drink on average each week?	No.	Col %	Cum %
1 - None	278	14.0	14.0
2 - Less than 7	675	33.9	47.8
3 - 7-14	290	14.6	62.4
4 - 15-21	112	5.6	68.0
5 - 22-28	58	2.9	70.9
6 - 28-35	22	1.1	72.0
7 - 36 or more	18	0.9	72.9
.a - Missing	539	27.1	100.0
Total	1992	100.0	

Notes:

A16 What brand of alcohol do you/did you normally drink?*hn2_a16_ay_brand*

Notes: • This is a free text field and will not be documented. Data for this variable are available through a standard data request.

A17 Are you currently working?*hn2_a17_ay_working*

- Categories
- Quality control
- Used to derive

Table 221: 4-months - AY: Are you currently working?

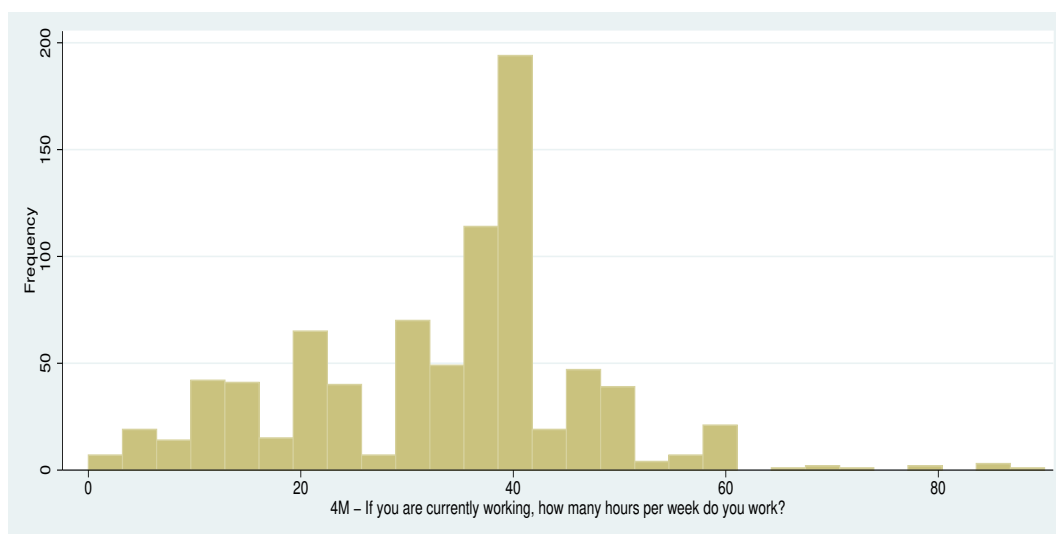
4M - Are you currently working:	No.	Col %	Cum %
1 - Yes	839	25.4	25.4
2 - No	2403	72.6	98.0
.a - Missing	67	2.0	100.0
Total	3309	100.0	

Notes:

A18 If you are currently working, how many hours per week do you work?*hn2_a18_ay_now_work_hours*

- Quality control
- Used to derive
- Descriptives:
 - Total valid responses = 824, number of missing values or data check errors = 2485

Figure 50: 4-months - 4-months - AY: If you are currently working, how many hours per week do you work?



Notes:

A21 What is your total household income from all sources before tax and other deductions?*hn2_a21_ay_hhold_income*

- Categories
 - Weekly
 - 1 Less than £77
 - 2 £77-154
 - 3 £155-£230
 - 4 £231-£346
 - 5 £347-£442
 - 6 £443-£558
 - 7 £559-£673
 - 8 £674+
 - Annually
 - 9 Less than £3999
 - 10 £4000-£7999
 - 11 £8000-£11999
 - 12 £12000-£17999
 - 13 £18000-£22999
 - 14 £23000-£28999
 - 15 £29000-£34999
 - 16 £35000+
- Quality control
- Used to derive
 - hn2_dv_a21_ay_hhold_income

Table 222: 4-months - AY: What is your total household income from all sources before tax and other deductions?

4M - What is your total household income	No.	Col %	Cum %
1 - Less than £77	75	2.3	2.3
2 - £77-154	214	6.5	8.7
3 - £155-£230	170	5.1	13.9
4 - £231-£346	150	4.5	18.4
5 - £347-£442	61	1.8	20.2
6 - £443-£558	27	0.8	21.1
7 - £559-£673	13	0.4	21.5
8 - £674 or more	19	0.6	22.0
9 - Less than £3999	39	1.2	23.2
10 - £4000-£7999	123	3.7	26.9
11 - £8000-£11999	208	6.3	33.2
12 - £12000-£17999	335	10.1	43.3
13 - £18000-£22999	223	6.7	50.1
14 - £23000-£28999	277	8.4	58.4
15 - £29000-34999	206	6.2	64.7
16 - £35000 or more	603	18.2	82.9
.a - Missing	566	17.1	100.0
Total	3309	100.0	

Notes:

A22 What proportion of your household income (including your own) would you say comes from benefits?*hn2_a22_ay_hhold_inc_benefit*

- Categories
- Quality control
- Used to derive

Table 223: 4-months - AY: What proportion of your household income (including your own) would you say comes from benefits?

4M - What proportion of your household income:	No.	Col %	Cum %
1 - None	1914	57.8	57.8
2 - About a quarter	168	5.1	62.9
3 - About three quarters	92	2.8	65.7
4 - Very little	336	10.2	75.9
5 - About half	132	4.0	79.8
6 - All	461	13.9	93.8
.a - Missing	206	6.2	100.0
Total	3309	100.0	

Notes:

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

Table 224: 4-months - AY: At present do you have any concerns about any of the following aspects of living with or after cancer?

- None - *hn2_a23a_ay_lc_none*

4M - Aspects of living with or after cancer: None	No.	Col %	Cum %
1 - Yes	1897	57.3	57.3
2 - No	1261	38.1	95.4
.a - Missing	151	4.6	100.0
Total	3309	100.0	

- Financial concerns - *hn2_a23b_ay_lc_financial*

4M - Aspects of living with or after cancer: Financial concerns	No.	Col %	Cum %
1 - Yes	862	26.1	26.1
2 - No	2297	69.4	95.5
.a - Missing	150	4.5	100.0
Total	3309	100.0	

- Staying in college/work - *hn2_a23c_ay_lc_stay_work*

4M - Aspects of living with or after cancer: Staying in work/college	No.	Col %	Cum %
1 - Yes	257	7.8	7.8
2 - No	2902	87.7	95.5
.a - Missing	150	4.5	100.0
Total	3309	100.0	

- Cost of attending appointments - *hn2_a23d_ay_lc_cost*

4M - Aspects of living with or after cancer: Cost of attending appointments	No.	Col %	Cum %
1 - Yes	436	13.2	13.2
2 - No	2724	82.3	95.5
.a - Missing	149	4.5	100.0
Total	3309	100.0	

- Taking time off work/college - *hn2_a23e_ay_lc_time_off*

4M - Aspects of living with or after cancer: Taking time off work/college	No.	Col %	Cum %
1 - Yes	353	10.7	10.7
2 - No	2806	84.8	95.5
.a - Missing	150	4.5	100.0
Total	3309	100.0	

- Returning to work/college - *hn2_a23f_ay_lc_return_work*

4M - Aspects of living with or after cancer: Returning to work/college	No.	Col %	Cum %
1 - Yes	439	13.3	13.3
2 - No	2720	82.2	95.5
.a - Missing	150	4.5	100.0
Total	3309	100.0	

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

hn2_a24_ay_what_you_do

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 225: 4-months - AY: Please tick the box that describes best what you can do:

4M - Please tick the box that describes best what you can do	No.	Col %	Cum %
1 - Able to carry out all normal activities without restriction	480	14.5	14.5
2 - Restricted in physically strenuous activity but able to walk and do light work	712	21.5	36.0
3 - Able to walk and all self care but unable to carry out any work up and about more than 50% of waking hours	356	10.8	46.8
4 - Capable of only limited self care confined to bed or chair more than 50% of waking hours	90	2.7	49.5
	5	0.2	49.7
.a - Missing	1666	50.3	100.0
Total	3309	100.0	

Notes:

A25 Please indicate which statements best describes your own health state today**Table 226:** 4-months - AY: Please indicate which statements best describes your own health state todaya) Mobility - *hn2_a25a_ay_hlth_mobility*

4M - Mobility	No.	Col %	Cum %
1 - I have no problems walking about	900	27.2	27.2
2 - I have slight problems walking about	364	11.0	38.2
3 - I have moderate problems walking about	272	8.2	46.4
4 - I have severe problems walking about	109	3.3	49.7
5 - I am unable to walk about	4	0.1	49.8
.a - Missing	1660	50.2	100.0
Total	3309	100.0	

b) Self care - *hn2_a25b_ay_hlth_self_care*

4M - Self care	No.	Col %	Cum %
1 - I have no prob washing or dressing myself	1307	39.5	39.5
2 - I have slight prob washing or dressing myself	198	6.0	45.5
3 - I have moderat prob washing or dressing myself	120	3.6	49.1
4 - I have svr prob washing or dressing myself	20	0.6	49.7
5 - I am unable to wash or dress myself	3	0.1	49.8
.a - Missing	1661	50.2	100.0
Total	3309	100.0	

c) Usual activities - *hn2_a25c_ay_hlth_usual_activ*

4M - Usual activities	No.	Col %	Cum %
1 - I have no prob with doing usual activities	593	17.9	17.9
2 - I have slight probs with doing usual activities	536	16.2	34.1
3 - I have mod probs doing usual activities	347	10.5	44.6
4 - I have sevr probs doing usual activities	118	3.6	48.2
5 - I am unable to do usual actvts	48	1.5	49.6
.a - Missing	1667	50.4	100.0
Total	3309	100.0	

d) Pain discomfort - *hn2_a25d_ay_hlth_pain*

4M - Pain discomfort	No.	Col %	Cum %
1 - I have no pain or discomfort	346	10.5	10.5
2 - I have slight pain or discomfort	682	20.6	31.1
3 - I have moderate pain or discomfort	463	14.0	45.1
4 - I have severe pain or discomfort	136	4.1	49.2
5 - I have extreme pain of discomfort	25	0.8	49.9
.a - Missing	1657	50.1	100.0
Total	3309	100.0	

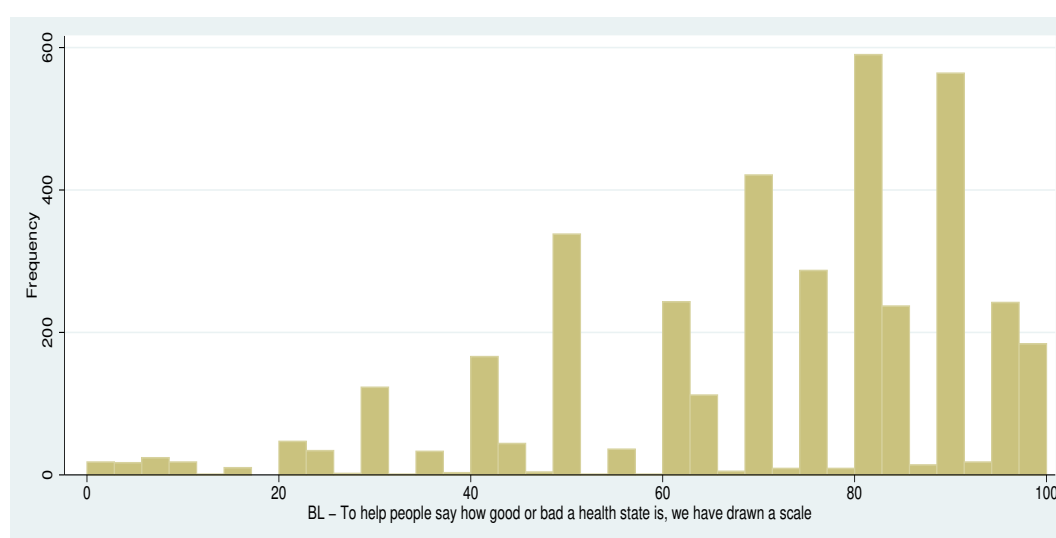
e) Anxiety/depression - *hn2_a25e_ay_hlth_anxiety*

4M - Anxiety/depression	No.	Col %	Cum %
1 - I am not anxious or depressed	730	22.1	22.1
2 - I am slightly anxious or depressed	579	17.5	39.6
3 - I am moderately anxious or depressed	271	8.2	47.7
4 - I am severely anxious or depressed	46	1.4	49.1
5 - I am extremely anxious or depressed	15	0.5	49.6
.a - Missing	1668	50.4	100.0
Total	3309	100.0	

Notes: • Early versions of the 4M - About You questionnaire did not include the EQ5D questionnaire. Response rates for these questions are consequently reduced.

A26 Please describe how good or bad your health state is today*hn2_a26_ay_hlth_state_scale*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 1645, number of missing values or data check errors = 1664

Figure 51: 4-months - AY: Please describe how good or bad your health state is today

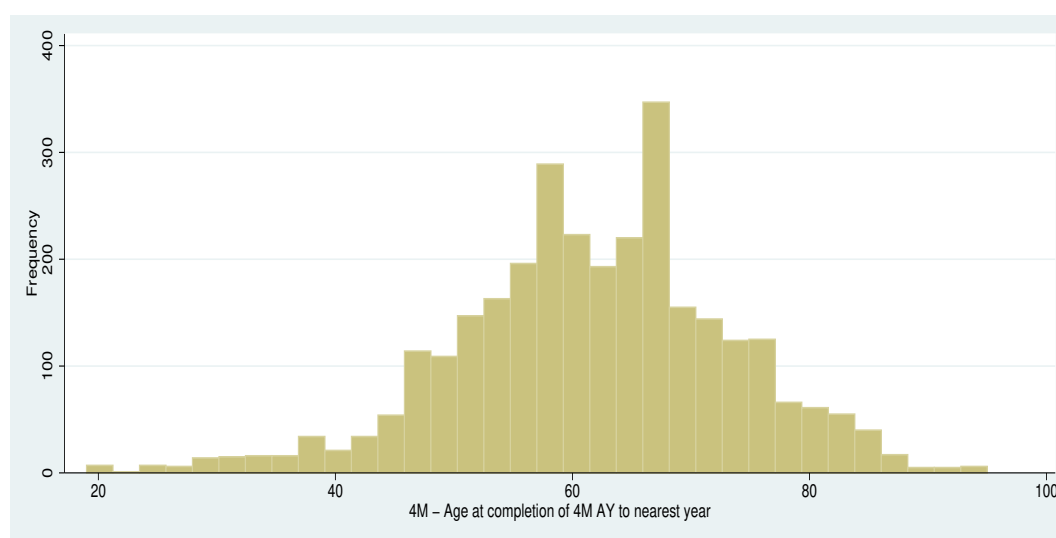
Notes:

- Early versions of the 4M - About You questionnaire did not include the EQ5D questionnaire. Response rates for these questions are consequently reduced.

4.2.2 About You - Derived Variables

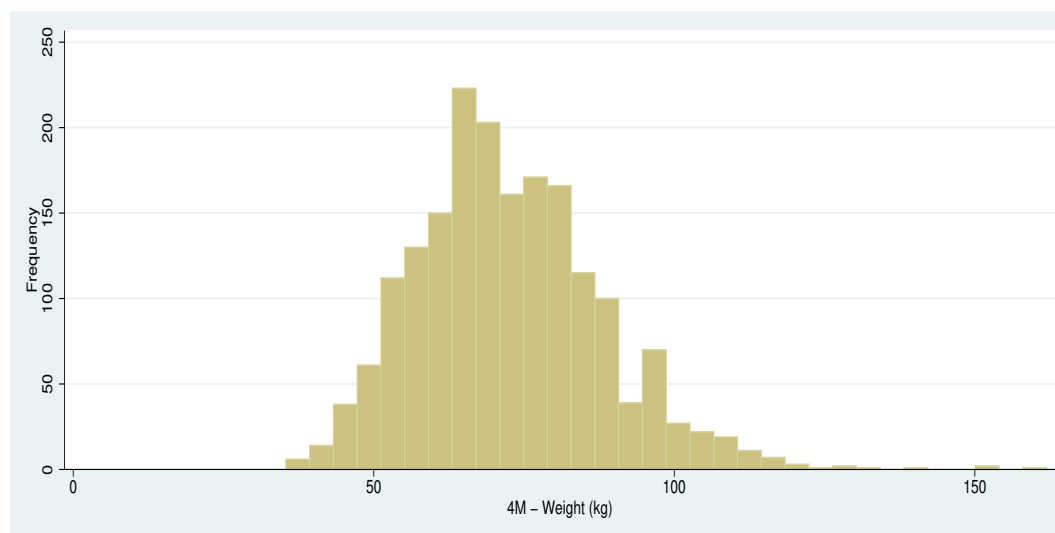
A1 comp Age at completion of 4M AY (days)*hn2_dv_ay_age*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 3029, number of missing values or data check errors = 280

Figure 52: 4M - AY: Age at completion of 4M AY (days)**Notes:**

A4 comp Composite variable - weight (kg)*hn2_dv_weight_kg*

- **Data check**
 - replace hn1_dv_weight_kg=. if hn1_dv_weight_kg<20
- **Used to derive:**
 - *hn2_dv_BMI*
- **Stata code to derive variable:**
 - gen hn2_dv_weight_kg = .
 - replace hn2_dv_weight_kg = hn2_a4_a_ay_kg_weight
 - replace hn2_dv_weight_kg = (hn2_a4_b1_ay_stone_weight * 6.35029) if hn2_a4_b1_ay_stone_weight<.
 - replace hn2_dv_weight_kg = (hn2_a4_b1_ay_stone_weight * 6.35029) + (hn2_a4_b2_ay_lbs_weight * 0.453592) if hn2_a4_b1_ay_stone_weight<.& hn2_a4_b2_ay_lbs_weight<.
- **Descriptives:**
 - Total valid responses = 1856, number of missing values or data check errors = 1453

Figure 53: 4-months - AY: Composite variable - weight (kg)**Notes:**

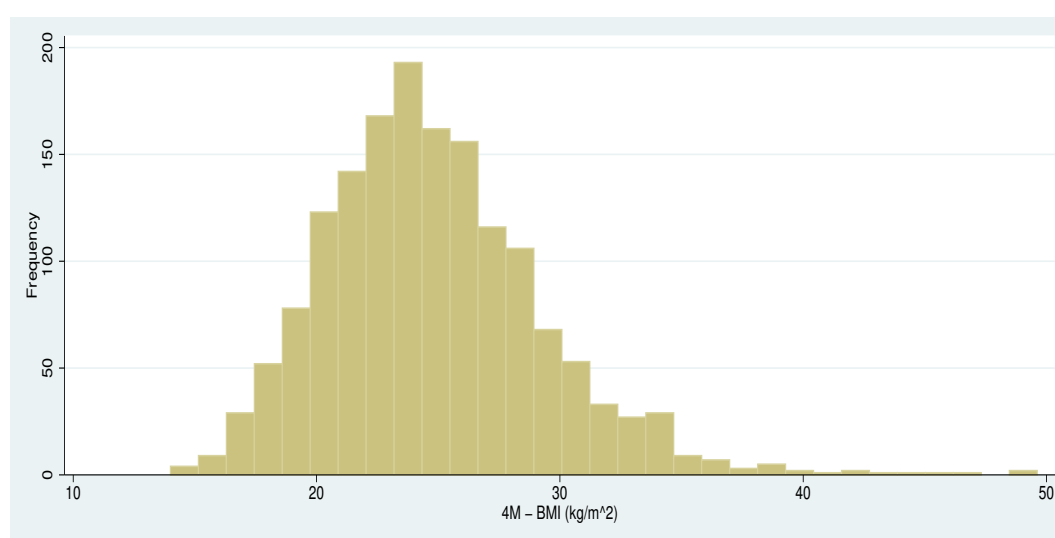
A3-4 comp Composite variable - BMI (kg/m²)*hn2_dv_BMI*

- **Stata code to derive variable:**

- `gen hn2_dv_BMI = hn2_dv_weight_kg/(hn1_dv_height_m^2)`

- **Descriptives:**

- Total valid responses = 1583, number of missing values or data check errors = 1726

Figure 54: 4-months - AY: Composite variable - BMI (kg/m²)**Notes:**

A13-comp1 Are you a current consumer of alcohol?*hn2_dv_drink_ever*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

Table 227: 4-months - AY: Are you a current consumer of alcohol?

4M - Current alcohol consumer	No.	Col %	Cum %
0 - No/never	1433	43.3	43.3
1 - Yes	1543	46.6	89.9
.a - Missing	333	10.1	100.0
Total	3309	100.0	

Notes:

A13-comp2 How many days per week do you drink alcohol?*hn2_dv_drink_days*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

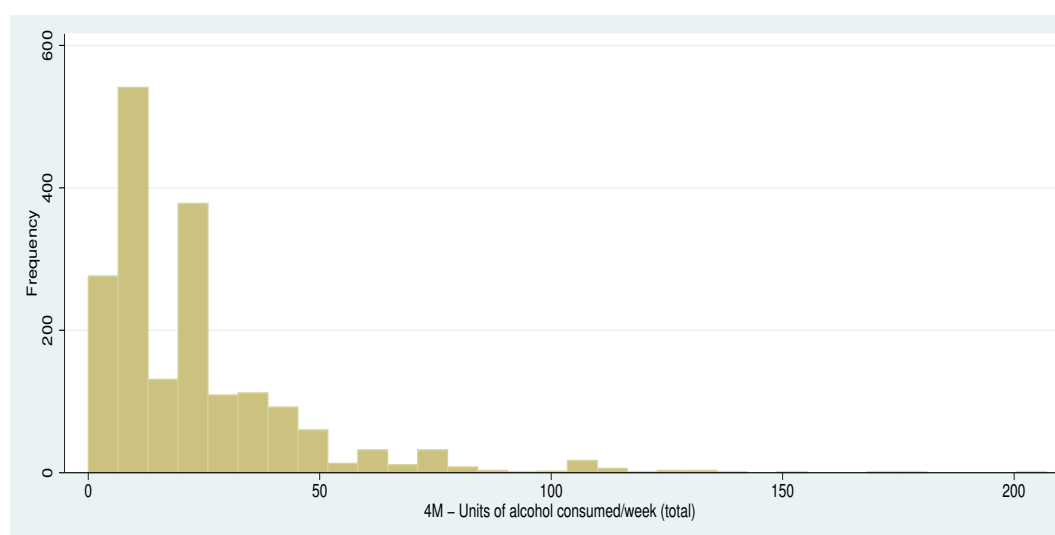
Table 228: 4-months - AY: How many days per week do you drink alcohol?

4M - Days per week alcohol consumed	No.	Col %	Cum %
0 - 0	1433	43.3	43.3
1 - 1	292	8.8	52.1
2 - 2	343	10.4	62.5
3 - 3	236	7.1	69.6
4 - 4	153	4.6	74.3
5 - 5	174	5.3	79.5
6 - 6	46	1.4	80.9
7 - 7	299	9.0	89.9
.a - Missing	333	10.1	100.0
Total	3309	100.0	

Notes:

A13-comp3 What is your total weekly alcohol consumption (units)?*hn2_dv_total_wk*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**
 - Total valid responses = 1836, number of missing values or data check errors = 1473

Figure 55: What is your total weekly alcohol consumption (units)?**Notes:**

4.2.3 Your Outlook

The topics covered in the ‘Your Outlook’ questionnaire are based on the ‘Revised Life Orientation Test (LOT-R)’ (Scheier et al., 1994). Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

B1 In uncertain times, I usually expect the best. - *hn2_b1_yo_uncertain_times*

Table 229: 4-months - LOT-R: In uncertain times, I usually expect the best.

4M - In uncertain times:	No.	Col %	Cum %
1 - Strongly disagree	72	2.2	2.2
2 - Disagree	477	14.4	16.6
3 - Neutral	1027	31.0	47.6
4 - Agree	1397	42.2	89.8
5 - Strongly agree	248	7.5	97.3
.a - Missing	88	2.7	100.0
Total	3309	100.0	

B2 It's easy for me to relax. - *hn2_b2_yo_relax*

Table 230: 4-months - LOT-R: It's easy for me to relax.

4M - It is easy for me to relax:	No.	Col %	Cum %
1 - Strongly disagree	115	3.5	3.5
2 - Disagree	754	22.8	26.3
3 - Neutral	688	20.8	47.1
4 - Agree	1380	41.7	88.8
5 - Strongly agree	233	7.0	95.8
.a - Missing	139	4.2	100.0
Total	3309	100.0	

B3 If something can go wrong for me, it will. - *hn2_b3_yo_go_wrong*

Table 231: 4-months - LOT-R: If something can go wrong for me, it will.

4M - If something can go wrong for me:	No.	Col %	Cum %
1 - Strongly disagree	314	9.5	9.5
2 - Disagree	1093	33.0	42.5
3 - Neutral	916	27.7	70.2
4 - Agree	723	21.8	92.1
5 - Strongly agree	133	4.0	96.1
.a - Missing	130	3.9	100.0
Total	3309	100.0	

B4 I'm always optimistic about my future - *hn2_b4_yo_optimistic***Table 232:** 4-months - LOT-R: I'm always optimistic about my future

4M - I am always optimistic about my future:	No.	Col %	Cum %
1 - Strongly disagree	74	2.2	2.2
2 - Disagree	413	12.5	14.7
3 - Neutral	866	26.2	40.9
4 - Agree	1531	46.3	87.2
5 - Strongly agree	343	10.4	97.5
.a - Missing	82	2.5	100.0
Total	3309	100.0	

B5 I enjoy my friends a lot. - *hn2_b5_yo_friends***Table 233:** 4-months - LOT-R: I enjoy my friends a lot.

4M - I enjoy my friends a lot:	No.	Col %	Cum %
1 - Strongly disagree	39	1.2	1.2
2 - Disagree	117	3.5	4.7
3 - Neutral	532	16.1	20.8
4 - Agree	1714	51.8	72.6
5 - Strongly agree	843	25.5	98.1
.a - Missing	64	1.9	100.0
Total	3309	100.0	

B6 It's important for me to keep busy - *hn2_b6_yo_keep_busy***Table 234:** 4-months - LOT-R: It's important for me to keep busy

4M - It is important for me to keep busy:	No.	Col %	Cum %
1 - Strongly disagree	35	1.1	1.1
2 - Disagree	207	6.3	7.3
3 - Neutral	652	19.7	27.0
4 - Agree	1657	50.1	77.1
5 - Strongly agree	670	20.2	97.3
.a - Missing	88	2.7	100.0
Total	3309	100.0	

B7 I hardly ever expect things to go my way. - *hn2_b7_yo_go_my_way*

Table 235: 4-months - LOT-R: I hardly ever expect things to go my way.

4M - I hardly ever expect things to go my way:	No.	Col %	Cum %
1 - Strongly disagree	389	11.8	11.8
2 - Disagree	1240	37.5	49.2
3 - Neutral	945	28.6	77.8
4 - Agree	555	16.8	94.6
5 - Strongly agree	99	3.0	97.6
.a - Missing	81	2.4	100.0
Total	3309	100.0	

B8 I don't get upset too easily. - *hn2_b8_yo_upset*

Table 236: 4-months - LOT-R: I don't get upset too easily.

4M - I do not get upset too easily:	No.	Col %	Cum %
1 - Strongly disagree	108	3.3	3.3
2 - Disagree	603	18.2	21.5
3 - Neutral	738	22.3	43.8
4 - Agree	1525	46.1	89.9
5 - Strongly agree	269	8.1	98.0
.a - Missing	66	2.0	100.0
Total	3309	100.0	

B9 I rarely count on good things happening to me. - *hn2_b9_yo_good_things*

Table 237: 4-months - LOT-R: I rarely count on good things happening to me.

4M - I rarely count on good things happening to me:	No.	Col %	Cum %
1 - Strongly disagree	317	9.6	9.6
2 - Disagree	1047	31.6	41.2
3 - Neutral	1020	30.8	72.0
4 - Agree	745	22.5	94.6
5 - Strongly agree	110	3.3	97.9
.a - Missing	70	2.1	100.0
Total	3309	100.0	

B10 Overall, I expect more good things to happen to me than bad. - *hn2_b10_yo_overall*

Table 238: 4-months - LOT-R: Overall, I expect more good things to happen to me than bad.

4M - Overall, I expect more good things to happen to me than bad.:	No.	Col %	Cum %
1 - Strongly disagree	73	2.2	2.2
2 - Disagree	357	10.8	13.0
3 - Neutral	945	28.6	41.6
4 - Agree	1562	47.2	88.8
5 - Strongly agree	311	9.4	98.2
.a - Missing	61	1.8	100.0
Total	3309	100.0	

Notes:

4.2.4 Your General Health - EORTC QLQ-C30

The topics covered in the 'Your General Health' questionnaire are based on the 'EORTC QLQ-C30' questionnaire (Aaronson et al., 1993). Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

C1 Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? - *hn2_c1_ygh_stren_acttrouble*

Table 239: 4-months - QLQ-C30: Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?

4M - Do you have any trouble doing strenuous activities,like carrying a heavy sh	No.	Col %	Cum %
1 - Not at all	921	27.8	27.8
2 - A little	1154	34.9	62.7
3 - Quite a bit	639	19.3	82.0
4 - Very much	556	16.8	98.8
.a - Missing	39	1.2	100.0
Total	3309	100.0	

C2 Do you have any trouble taking a long walk? - *hn2_c2_ygh_long_walktrouble*

Table 240: 4-months - QLQ-C30: Do you have any trouble taking a long walk?

4M - Do you have any trouble taking a long walk?	No.	Col %	Cum %
1 - Not at all	970	29.3	29.3
2 - A little	1030	31.1	60.4
3 - Quite a bit	560	16.9	77.4
4 - Very much	681	20.6	97.9
.a - Missing	68	2.1	100.0
Total	3309	100.0	

C3 Do you have any trouble taking a short walk outside of the house? - *hn2_c3_ygh_short_walktrouble*

Table 241: 4-months - QLQ-C30: Do you have any trouble taking a short walk outside of the house?

4M - Do you have any trouble taking a short walk outside of the house?	No.	Col %	Cum %
1 - Not at all	2221	67.1	67.1
2 - A little	638	19.3	86.4
3 - Quite a bit	274	8.3	94.7
4 - Very much	135	4.1	98.8
.a - Missing	41	1.2	100.0
Total	3309	100.0	

C4 Do you need to stay in bed or a chair during the day? - *hn2_c4_ygh_stay_bed_daytime*

Table 242: 4-months - QLQ-C30: Do you need to stay in bed or a chair during the day?

4M - Do you need to stay in bed or a chair during the day?	No.	Col %	Cum %
1 - Not at all	1810	54.7	54.7
2 - A little	876	26.5	81.2
3 - Quite a bit	431	13.0	94.2
4 - Very much	115	3.5	97.7
.a - Missing	77	2.3	100.0
Total	3309	100.0	

C5 Do you need help with eating, dressing, washing yourself or using the toilet? - *hn2_c5_ygh_help_with_eating*

Table 243: 4-months - QLQ-C30: Do you need help with eating, dressing, washing yourself or using the toilet?

4M - Do you need help with eating, dressing, washing yourself or using the toile	No.	Col %	Cum %
1 - Not at all	2856	86.3	86.3
2 - A little	290	8.8	95.1
3 - Quite a bit	72	2.2	97.2
4 - Very much	45	1.4	98.6
.a - Missing	46	1.4	100.0
Total	3309	100.0	

C6 Were you limited in doing either your work or other daily activities? - *hn2_c6_ygh_limit_daily_activ*

Table 244: 4-months - QLQ-C30: Were you limited in doing either your work or other daily activities?

4M - Were you limited in doing either your work or other daily activities?	No.	Col %	Cum %
1 - Not at all	1247	37.7	37.7
2 - A little	1109	33.5	71.2
3 - Quite a bit	554	16.7	87.9
4 - Very much	356	10.8	98.7
.a - Missing	43	1.3	100.0
Total	3309	100.0	

C7 Were you limited in pursuing your hobbies or other leisure time activities? - *hn2_c7_ygh_limit_hobbies*

Table 245: 4-months - QLQ-C30: Were you limited in pursuing your hobbies or other leisure time activities?

4M - Were you limited in pursuing your hobbies or other leisure time activities?	No.	Col %	Cum %
1 - Not at all	1279	38.7	38.7
2 - A little	916	27.7	66.3
3 - Quite a bit	602	18.2	84.5
4 - Very much	455	13.8	98.3
.a - Missing	57	1.7	100.0
Total	3309	100.0	

C8 Were you short of breath? - *hn2_c8_ygh_short_of_breath*

Table 246: 4-months - QLQ-C30: Were you short of breath?

4M - Were you short of breath?	No.	Col %	Cum %
1 - Not at all	1913	57.8	57.8
2 - A little	909	27.5	85.3
3 - Quite a bit	278	8.4	93.7
4 - Very much	151	4.6	98.2
.a - Missing	58	1.8	100.0
Total	3309	100.0	

C9 Have you had pain? - *hn2_c9_ygh_had_pain*

Table 247: 4-months - QLQ-C30: Have you had pain?

4M - Have you had pain?	No.	Col %	Cum %
1 - Not at all	1018	30.8	30.8
2 - A little	1362	41.2	71.9
3 - Quite a bit	576	17.4	89.3
4 - Very much	315	9.5	98.9
.a - Missing	38	1.1	100.0
Total	3309	100.0	

C10 Did you need to rest? - *hn2_c10_ygh_need_to_rest*

Table 248: 4-months - QLQ-C30: Did you need to rest?

4M - Did you need to rest?	No.	Col %	Cum %
1 - Not at all	660	19.9	19.9
2 - A little	1442	43.6	63.5
3 - Quite a bit	768	23.2	86.7
4 - Very much	389	11.8	98.5
.a - Missing	50	1.5	100.0
Total	3309	100.0	

C11 Have you had trouble sleeping? - *hn2_c11_ygh_sleep_trouble*

Table 249: 4-months - QLQ-C30: Have you had trouble sleeping?

4M - Have you had trouble sleeping?	No.	Col %	Cum %
1 - Not at all	1122	33.9	33.9
2 - A little	1143	34.5	68.4
3 - Quite a bit	618	18.7	87.1
4 - Very much	394	11.9	99.0
.a - Missing	32	1.0	100.0
Total	3309	100.0	

C12 Have you felt weak? - *hn2_c12_ygh_felt_weak*

Table 250: 4-months - QLQ-C30: Have you felt weak?

4M - Have you felt weak?	No.	Col %	Cum %
1 - Not at all	815	24.6	24.6
2 - A little	1288	38.9	63.6
3 - Quite a bit	662	20.0	83.6
4 - Very much	499	15.1	98.6
.a - Missing	45	1.4	100.0
Total	3309	100.0	

C13 Have you lacked appetite? - *hn2_c13_ygh_lacked_appetite***Table 251:** 4-months - QLQ-C30: Have you lacked appetite?

4M - Have you lacked appetite?	No.	Col %	Cum %
1 - Not at all	1194	36.1	36.1
2 - A little	843	25.5	61.6
3 - Quite a bit	554	16.7	78.3
4 - Very much	658	19.9	98.2
.a - Missing	60	1.8	100.0
Total	3309	100.0	

C14 Have you felt nauseated? - *hn2_c14_ygh_felt_auseated***Table 252:** 4-months - QLQ-C30: Have you felt nauseated?

4M - Have you felt nauseated?	No.	Col %	Cum %
1 - Not at all	2081	62.9	62.9
2 - A little	767	23.2	86.1
3 - Quite a bit	248	7.5	93.6
4 - Very much	174	5.3	98.8
.a - Missing	39	1.2	100.0
Total	3309	100.0	

C15 Have you vomited? - *hn2_c15_ygh_vomited***Table 253:** 4-months - QLQ-C30: Have you vomited?

4M - Have you vomited?	No.	Col %	Cum %
1 - Not at all	2673	80.8	80.8
2 - A little	424	12.8	93.6
3 - Quite a bit	98	3.0	96.6
4 - Very much	75	2.3	98.8
.a - Missing	39	1.2	100.0
Total	3309	100.0	

C16 Have you been constipated? - *hn2_c16_ygh_constipated*

Table 254: 4-months - QLQ-C30: Have you been constipated?

4M - Have you been constipated?	No.	Col %	Cum %
1 - Not at all	1808	54.6	54.6
2 - A little	886	26.8	81.4
3 - Quite a bit	370	11.2	92.6
4 - Very much	199	6.0	98.6
.a - Missing	46	1.4	100.0
Total	3309	100.0	

C17 Have you had diarrhoea? - *hn2_c17_ygh_diarrhoea*

Table 255: 4-months - QLQ-C30: Have you had diarrhoea?

4M - Have you had diarrhoea?	No.	Col %	Cum %
1 - Not at all	2616	79.1	79.1
2 - A little	496	15.0	94.0
3 - Quite a bit	104	3.1	97.2
4 - Very much	51	1.5	98.7
.a - Missing	42	1.3	100.0
Total	3309	100.0	

C18 Were you tired? - *hn2_c18_ygh_tired*

Table 256: 4-months - QLQ-C30: Were you tired?

4M - Were you tired?	No.	Col %	Cum %
1 - Not at all	440	13.3	13.3
2 - A little	1447	43.7	57.0
3 - Quite a bit	825	24.9	82.0
4 - Very much	507	15.3	97.3
.a - Missing	90	2.7	100.0
Total	3309	100.0	

C19 Did pain interfere with your daily activities? - *hn2_c19_ygh_pain_daily_activ*

Table 257: 4-months - QLQ-C30: Did pain interfere with your daily activities?

4M - Did pain interfere with your daily activities?	No.	Col %	Cum %
1 - Not at all	1675	50.6	50.6
2 - A little	997	30.1	80.7
3 - Quite a bit	396	12.0	92.7
4 - Very much	206	6.2	98.9
.a - Missing	35	1.1	100.0
Total	3309	100.0	

C20 Have you had difficulty in concentrating on things, like reading a newspaper or watching television? - *hn2_c20_ygh_difficulty_conc*

Table 258: 4-months - QLQ-C30: Have you had difficulty in concentrating on things, like reading a newspaper or watching television?

4M - Have you had difficulty in concentrating on things, like reading a newspaper	No.	Col %	Cum %
1 - Not at all	1804	54.5	54.5
2 - A little	963	29.1	83.6
3 - Quite a bit	357	10.8	94.4
4 - Very much	146	4.4	98.8
.a - Missing	39	1.2	100.0
Total	3309	100.0	

C21 Did you feel tense? - *hn2_c21_ygh_feel_tense*

Table 259: 4-months - QLQ-C30: Did you feel tense?

4M - Did you feel tense?	No.	Col %	Cum %
1 - Not at all	1449	43.8	43.8
2 - A little	1269	38.3	82.1
3 - Quite a bit	410	12.4	94.5
4 - Very much	139	4.2	98.7
.a - Missing	42	1.3	100.0
Total	3309	100.0	

C22 Did you worry? - *hn2_c22_ygh_worry***Table 260:** 4-months - QLQ-C30: Did you worry?

4M - Did you worry?	No.	Col %	Cum %
1 - Not at all	1068	32.3	32.3
2 - A little	1507	45.5	77.8
3 - Quite a bit	482	14.6	92.4
4 - Very much	214	6.5	98.9
.a - Missing	38	1.1	100.0
Total	3309	100.0	

C23 Did you feel irritable? - *hn2_c23_ygh_irritable***Table 261:** 4-months - QLQ-C30: Did you feel irritable?

4M - Did you feel irritable?	No.	Col %	Cum %
1 - Not at all	1276	38.6	38.6
2 - A little	1406	42.5	81.1
3 - Quite a bit	432	13.1	94.1
4 - Very much	159	4.8	98.9
.a - Missing	36	1.1	100.0
Total	3309	100.0	

C24 Did you feel depressed? - *hn2_c24_ygh_depressed***Table 262:** 4-months - QLQ-C30: Did you feel depressed?

4M - Did you feel depressed?	No.	Col %	Cum %
1 - Not at all	1683	50.9	50.9
2 - A little	1082	32.7	83.6
3 - Quite a bit	337	10.2	93.7
4 - Very much	167	5.0	98.8
.a - Missing	40	1.2	100.0
Total	3309	100.0	

C25 Have you had difficulty remembering things? - *hn2_c25_ygh_mem_diff*

Table 263: 4-months - QLQ-C30: Have you had difficulty remembering things?

4M - Have you had difficulty remembering things?	No.	Col %	Cum %
1 - Not at all	1522	46.0	46.0
2 - A little	1281	38.7	84.7
3 - Quite a bit	347	10.5	95.2
4 - Very much	127	3.8	99.0
.a - Missing	32	1.0	100.0
Total	3309	100.0	

C26 Has your physical condition or medical treatment interfered with your family life? - *hn2_c26_ygh_family_life*

Table 264: 4-months - QLQ-C30: Has your physical condition or medical treatment interfered with your family life?

4M - Has your physical condition or medical treatment interfered with your famil	No.	Col %	Cum %
1 - Not at all	1314	39.7	39.7
2 - A little	1171	35.4	75.1
3 - Quite a bit	498	15.0	90.1
4 - Very much	278	8.4	98.5
.a - Missing	48	1.5	100.0
Total	3309	100.0	

C27 Has your physical condition or medical treatment interfered with your social activities? - *hn2_c27_ygh_social_activ*

Table 265: 4-months - QLQ-C30: Has your physical condition or medical treatment interfered with your social activities?

4M - Has your physical condition or medical treatment interfered with your socia	No.	Col %	Cum %
1 - Not at all	934	28.2	28.2
2 - A little	1085	32.8	61.0
3 - Quite a bit	700	21.2	82.2
4 - Very much	549	16.6	98.8
.a - Missing	41	1.2	100.0
Total	3309	100.0	

C28 Has your physical condition or medical treatment interfered caused you financial difficulties?

- *hn2_c28_ygh_financial_diff*

Table 266: 4-months - QLQ-C30: Has your physical condition or medical treatment interfered caused you financial difficulties?

4M - Has your physical condition or medical treatment caused you financial diffi	No.	Col %	Cum %
1 - Not at all	1894	57.2	57.2
2 - A little	759	22.9	80.2
3 - Quite a bit	319	9.6	89.8
4 - Very much	292	8.8	98.6
.a - Missing	45	1.4	100.0
Total	3309	100.0	

C29 How would you rate your overall health during the past week? - *hn2_c29_ygh_health_past_wk*

Table 267: 4-months - QLQ-C30: How would you rate your overall health during the past week?

4M - How would you rate your overall health during the past week?(on a scale of	No.	Col %	Cum %
1 - Very poor	106	3.2	3.2
2 - 2	174	5.3	8.5
3 - 3	469	14.2	22.6
4 - 4	729	22.0	44.7
5 - 5	912	27.6	72.2
6 - 6	699	21.1	93.4
7 - Excellent	187	5.7	99.0
.a - Missing	33	1.0	100.0
Total	3309	100.0	

C30 How would you rate your overall quality of life during the past week? - *hn2_c30_ygh_lifequal_past_wk*

Table 268: 4-months - QLQ-C30: How would you rate your overall quality of life during the past week?

4M - How would you rate your overall quality of life during the past week?	No.	Col %	Cum %
1 - Very poor	119	3.6	3.6
2 - 2	195	5.9	9.5
3 - 3	449	13.6	23.1
4 - 4	628	19.0	42.0
5 - 5	807	24.4	66.4
6 - 6	782	23.6	90.1
7 - Excellent	294	8.9	98.9
.a - Missing	35	1.1	100.0
Total	3309	100.0	

Notes:

4.2.5 Specific Aspects of Your health

The topics covered in the ‘Specific Aspects of Your health’ questionnaire are based on the ‘EORTC QLQ-H&N35’ questionnaire (Bjordal et al., 1993). Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

D1 Have you had pain in the mouth? - *hn2_d1_sayh_pain_mouth*

Table 269: 4-months - HN35: Have you had pain in the mouth?

4M - Have you had pain in your mouth:	No.	Col %	Cum %
1 - Not at all	1299	39.3	39.3
2 - A little	1067	32.2	71.5
3 - Quite a bit	566	17.1	88.6
4 - Very much	344	10.4	99.0
.a - Missing	33	1.0	100.0
Total	3309	100.0	

D2 Have you had pain in the jaw? - *hn2_d2_sayh_pain_jaw*

Table 270: 4-months - HN35: Have you had pain in the jaw?

4M - Have you had pain in your jaw:	No.	Col %	Cum %
1 - Not at all	1921	58.1	58.1
2 - A little	868	26.2	84.3
3 - Quite a bit	308	9.3	93.6
4 - Very much	157	4.7	98.3
.a - Missing	55	1.7	100.0
Total	3309	100.0	

D3 Have you had soreness in the mouth? - *hn2_d3_sayh_soreness_mouth*

Table 271: 4-months - HN35: Have you had soreness in the mouth?

4M - Have you had soreness in your mouth:	No.	Col %	Cum %
1 - Not at all	1169	35.3	35.3
2 - A little	1130	34.1	69.5
3 - Quite a bit	577	17.4	86.9
4 - Very much	391	11.8	98.7
.a - Missing	42	1.3	100.0
Total	3309	100.0	

D4 Have you had a painful throat? - *hn2_d4_sayh_painful_throat*

Table 272: 4-months - HN35: Have you had a painful throat?

4M - Have you had problems swallowing liquid:	No.	Col %	Cum %
1 - Not at all	1231	37.2	37.2
2 - A little	1072	32.4	69.6
3 - Quite a bit	585	17.7	87.3
4 - Very much	374	11.3	98.6
.a - Missing	47	1.4	100.0
Total	3309	100.0	

D5 Have you had problems swallowing liquid? - *hn2_d5_sayh_swallow_liquid***Table 273:** 4-months - HN35: Have you had problems swallowing liquid?

4M - Have you had problems swallowing liquid:	No.	Col %	Cum %
1 - Not at all	1935	58.5	58.5
2 - A little	777	23.5	82.0
3 - Quite a bit	293	8.9	90.8
4 - Very much	270	8.2	99.0
.a - Missing	34	1.0	100.0
Total	3309	100.0	

D6 Have you had problems swallowing pureed food? - *hn2_d6_sayh_swallow_pureed***Table 274:** 4-months - HN35: Have you had problems swallowing pureed food?

4M - Have you had problems swallowing pureed food:	No.	Col %	Cum %
1 - Not at all	1997	60.4	60.4
2 - A little	608	18.4	78.7
3 - Quite a bit	244	7.4	86.1
4 - Very much	369	11.2	97.2
.a - Missing	91	2.8	100.0
Total	3309	100.0	

D7 Have you had problems swallowing solid food? - *hn2_d7_sayh_swallow_solid***Table 275:** 4-months - HN35: Have you had problems swallowing solid food?

4M - Have you had problems swallowing solid food:	No.	Col %	Cum %
1 - Not at all	1161	35.1	35.1
2 - A little	825	24.9	60.0
3 - Quite a bit	433	13.1	73.1
4 - Very much	815	24.6	97.7
.a - Missing	75	2.3	100.0
Total	3309	100.0	

D8 Have you choked when swallowing? - *hn2_d8_sayh_choked***Table 276:** 4-months - HN35: Have you choked when swallowing?

4M - Have you choked when swallowing:	No.	Col %	Cum %
1 - Not at all	2247	67.9	67.9
2 - A little	651	19.7	87.6
3 - Quite a bit	172	5.2	92.8
4 - Very much	161	4.9	97.6
.a - Missing	78	2.4	100.0
Total	3309	100.0	

D9 Have you had problems with teeth? - *hn2_d9_sayh_problems_teeth*

Table 277: 4-months - HN35: Have you had problems with teeth?

4M - Have you had problems with your teeth:	No.	Col %	Cum %
1 - Not at all	2052	62.0	62.0
2 - A little	694	21.0	83.0
3 - Quite a bit	231	7.0	90.0
4 - Very much	208	6.3	96.3
.a - Missing	124	3.7	100.0
Total	3309	100.0	

D10 Have you had problems opening mouth? - *hn2_d10_sayh_open_mouth*

Table 278: 4-months - HN35: Have you had problems opening mouth?

4M - Have you had problems opening your mouth wide:	No.	Col %	Cum %
1 - Not at all	1943	58.7	58.7
2 - A little	785	23.7	82.4
3 - Quite a bit	311	9.4	91.8
4 - Very much	230	7.0	98.8
.a - Missing	40	1.2	100.0
Total	3309	100.0	

D11 Have you had a dry mouth? - *hn2_d11_sayh_dry_mouth*

Table 279: 4-months - HN35: Have you had a dry mouth?

4M - Have you had a dry mouth:	No.	Col %	Cum %
1 - Not at all	716	21.6	21.6
2 - A little	808	24.4	46.1
3 - Quite a bit	734	22.2	68.2
4 - Very much	1020	30.8	99.1
.a - Missing	31	0.9	100.0
Total	3309	100.0	

D12 Have you had sticky saliva? - *hn2_d12_sayh_sticky_saliva*

Table 280: 4-months - HN35: Have you had sticky saliva?

4M - Have you had sticky saliva:	No.	Col %	Cum %
1 - Not at all	981	29.6	29.6
2 - A little	742	22.4	52.1
3 - Quite a bit	667	20.2	72.2
4 - Very much	867	26.2	98.4
.a - Missing	52	1.6	100.0
Total	3309	100.0	

D13 Have you had problems with your sense of smell? - *hn2_d13_sayh_sense_smell*

Table 281: 4-months - HN35: Have you had problems with your sense of smell?

4M - Have you had problems with your sense of smell:	No.	Col %	Cum %
1 - Not at all	2066	62.4	62.4
2 - A little	670	20.2	82.7
3 - Quite a bit	266	8.0	90.7
4 - Very much	275	8.3	99.0
.a - Missing	32	1.0	100.0
Total	3309	100.0	

D14 Have you had problems with your sense of taste? - *hn2_d14_sayh_sense_taste*

Table 282: 4-months - HN35: Have you had problems with your sense of taste?

4M - Have you had problems with your sense of taste:	No.	Col %	Cum %
1 - Not at all	970	29.3	29.3
2 - A little	821	24.8	54.1
3 - Quite a bit	567	17.1	71.3
4 - Very much	910	27.5	98.8
.a - Missing	41	1.2	100.0
Total	3309	100.0	

D15 Have you coughed? - *hn2_d15_sayh_coughed*

Table 283: 4-months - HN35: Have you coughed?

4M - Have you coughed:	No.	Col %	Cum %
1 - Not at all	838	25.3	25.3
2 - A little	1583	47.8	73.2
3 - Quite a bit	603	18.2	91.4
4 - Very much	239	7.2	98.6
.a - Missing	46	1.4	100.0
Total	3309	100.0	

D16 Have you been hoarse? - *hn2_d16_sayh_hoarse*

Table 284: 4-months - HN35: Have you been hoarse?

4M - Have you been hoarse:	No.	Col %	Cum %
1 - Not at all	1353	40.9	40.9
2 - A little	1092	33.0	73.9
3 - Quite a bit	507	15.3	89.2
4 - Very much	276	8.3	97.6
.a - Missing	81	2.4	100.0
Total	3309	100.0	

D17 Have you felt ill? - *hn2_d17_sayh_felt_ill*

Table 285: 4-months - HN35: Have you felt ill?

4M - Have you felt ill:	No.	Col %	Cum %
1 - Not at all	1644	49.7	49.7
2 - A little	1106	33.4	83.1
3 - Quite a bit	336	10.2	93.3
4 - Very much	167	5.0	98.3
.a - Missing	56	1.7	100.0
Total	3309	100.0	

D18 Has your appearance bothered you? - *hn2_d18_sayh_appearance*

Table 286: 4-months - HN35: Has your appearance bothered you?

4M - Has your appearance bothered you:	No.	Col %	Cum %
1 - Not at all	1741	52.6	52.6
2 - A little	967	29.2	81.8
3 - Quite a bit	325	9.8	91.7
4 - Very much	230	7.0	98.6
.a - Missing	46	1.4	100.0
Total	3309	100.0	

D19 Have you had trouble eating? - *hn2_d19_sayh_trouble_eating*

Table 287: 4-months - HN35: Have you had trouble eating?

4M - Have you had trouble eating:	No.	Col %	Cum %
1 - Not at all	1122	33.9	33.9
2 - A little	831	25.1	59.0
3 - Quite a bit	524	15.8	74.9
4 - Very much	761	23.0	97.9
.a - Missing	71	2.1	100.0
Total	3309	100.0	

D20 Have you had trouble eating in front of family? - *hn2_d20_sayh_front_family*

Table 288: 4-months - HN35: Have you had trouble eating in front of family?

4M - Have you had trouble eating in front of family:	No.	Col %	Cum %
1 - Not at all	2098	63.4	63.4
2 - A little	484	14.6	78.0
3 - Quite a bit	239	7.2	85.3
4 - Very much	345	10.4	95.7
.a - Missing	143	4.3	100.0
Total	3309	100.0	

D21 Have you had trouble eating in front of others? - *hn2_d21_sayh_front_others*

Table 289: 4-months - HN35: Have you had trouble eating in front of others?

4M - Have you had trouble eating in front of others:	No.	Col %	Cum %
1 - Not at all	1799	54.4	54.4
2 - A little	581	17.6	71.9
3 - Quite a bit	304	9.2	81.1
4 - Very much	476	14.4	95.5
.a - Missing	149	4.5	100.0
Total	3309	100.0	

D22 Have you had trouble enjoying meals? - *hn2_d22_sayh_enjoying*

Table 290: 4-months - HN35: Have you had trouble enjoying meals?

4M - Have you had trouble enjoying meals:	No.	Col %	Cum %
1 - Not at all	993	30.0	30.0
2 - A little	726	21.9	51.9
3 - Quite a bit	577	17.4	69.4
4 - Very much	899	27.2	96.6
.a - Missing	114	3.4	100.0
Total	3309	100.0	

D23 Have you had trouble talking to other people? - *hn2_d23_sayh_talking_people*

Table 291: 4-months - HN35: Have you had trouble talking to other people?

4M - Have you had trouble talking to other people:	No.	Col %	Cum %
1 - Not at all	1707	51.6	51.6
2 - A little	895	27.0	78.6
3 - Quite a bit	388	11.7	90.4
4 - Very much	282	8.5	98.9
.a - Missing	37	1.1	100.0
Total	3309	100.0	

D24 Have you had trouble talking on the telephone? - *hn2_d24_sayh_talking_phone*

Table 292: 4-months - HN35: Have you had trouble talking on the telephone?

4M - Have you had trouble talking on the telephone:	No.	Col %	Cum %
1 - Not at all	1557	47.1	47.1
2 - A little	893	27.0	74.0
3 - Quite a bit	403	12.2	86.2
4 - Very much	417	12.6	98.8
.a - Missing	39	1.2	100.0
Total	3309	100.0	

D25 Have you had trouble having social contact with family? - *hn2_d25_sayh_social_family*

Table 293: 4-months - HN35: Have you had trouble having social contact with family?

4M - Have you had trouble having social contact with family:	No.	Col %	Cum %
1 - Not at all	2377	71.8	71.8
2 - A little	510	15.4	87.2
3 - Quite a bit	209	6.3	93.6
4 - Very much	163	4.9	98.5
.a - Missing	50	1.5	100.0
Total	3309	100.0	

D26 Have you had trouble having social contact with friends? - *hn2_d26_sayh_social_friends*

Table 294: 4-months - HN35: Have you had trouble having social contact with friends?

4M - Have you had trouble having social contact with friends:	No.	Col %	Cum %
1 - Not at all	1987	60.0	60.0
2 - A little	707	21.4	81.4
3 - Quite a bit	305	9.2	90.6
4 - Very much	265	8.0	98.6
.a - Missing	45	1.4	100.0
Total	3309	100.0	

D27 Have you had trouble going out in public? - *hn2_d27_sayh_out_public*

Table 295: 4-months - HN35: Have you had trouble going out in public?

4M - Have you had trouble going out in public:	No.	Col %	Cum %
1 - Not at all	2154	65.1	65.1
2 - A little	623	18.8	83.9
3 - Quite a bit	275	8.3	92.2
4 - Very much	224	6.8	99.0
.a - Missing	33	1.0	100.0
Total	3309	100.0	

D28 Have you had trouble having physical contact with family or friends? - *hn2_d28_sayh_physical*

Table 296: 4-months - HN35: Have you had trouble having physical contact with family or friends?

4M - Have you had trouble having physical contact with family or friends:	No.	Col %	Cum %
1 - Not at all	2294	69.3	69.3
2 - A little	548	16.6	85.9
3 - Quite a bit	224	6.8	92.7
4 - Very much	172	5.2	97.9
.a - Missing	71	2.1	100.0
Total	3309	100.0	

D29 Have you felt less interest in sex? - *hn2_d29_sayh_sex*

Table 297: 4-months - HN35: Have you felt less interest in sex?

4M - Have you felt less interest in sex:	No.	Col %	Cum %
1 - Not at all	892	27.0	27.0
2 - A little	597	18.0	45.0
3 - Quite a bit	603	18.2	63.2
4 - Very much	880	26.6	89.8
.a - Missing	337	10.2	100.0
Total	3309	100.0	

D30 Have you felt less sexual enjoyment? - *hn2_d30_sayh_sex_enjoy*

Table 298: 4-months - HN35: Have you felt less sexual enjoyment?

4M - Have you felt less sexual enjoyment:	No.	Col %	Cum %
1 - Not at all	844	25.5	25.5
2 - A little	546	16.5	42.0
3 - Quite a bit	438	13.2	55.2
4 - Very much	806	24.4	79.6
.a - Missing	675	20.4	100.0
Total	3309	100.0	

D31 Have you used painkillers? - *hn2_d31_sayh_painkillers*

Table 299: 4-months - HN35: Have you used painkillers?

4M - Have you used painkillers:	No.	Col %	Cum %
1 - Yes	2014	60.9	60.9
2 - No	1260	38.1	98.9
.a - Missing	35	1.1	100.0
Total	3309	100.0	

D32 Have you taken any nutritional supplements (excluding vitamins)? - *hn2_d32_sayh_nutritional*

Table 300: 4-months - HN35: Have you taken any nutritional supplements (excluding vitamins)?

4M - Have you taken any nutritional supplements (excluding vitamins):	No.	Col %	Cum %
1 - Yes	1502	45.4	45.4
2 - No	1748	52.8	98.2
.a - Missing	59	1.8	100.0
Total	3309	100.0	

D33 Have you used a feeding tube? - *hn2_d33_sayh_feed_tube*

Table 301: 4-months - HN35: Have you used a feeding tube?

4M - Have you used a feeding tube:	No.	Col %	Cum %
1 - Yes	821	24.8	24.8
2 - No	2443	73.8	98.6
.a - Missing	45	1.4	100.0
Total	3309	100.0	

D34 Have you lost weight? - *hn2_d34_sayh_lost_wght*

Table 302: 4-months - HN35: Have you lost weight?

4M - Have you lost weight:	No.	Col %	Cum %
1 - Yes	1254	37.9	37.9
2 - No	1961	59.3	97.2
.a - Missing	94	2.8	100.0
Total	3309	100.0	

D35 Have you gained weight? - *hn2_d35_sayh_gained_wght*

Table 303: 4-months - HN35: Have you gained weight?

4M - Have you gained weight:	No.	Col %	Cum %
1 - Yes	753	22.8	22.8
2 - No	2386	72.1	94.9
.a - Missing	170	5.1	100.0
Total	3309	100.0	

4.2.6 Your Feelings

The topics covered in the ‘Your Feelings’ questionnaire are based on the ‘Hospital Anxiety and Depression Scale (HADS)’ questionnaire (Zigmond and Snaith, 1983). Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

E1 I feel tense or 'wound up': - *hn2_e1_yf_tense*

Table 304: 4-months - HADS: I feel tense or 'wound up'

4M - I feel tense or wound up:	No.	Col %	Cum %
1 - Most of the time	176	5.3	5.3
2 - A lot of the time	421	12.7	18.0
3 - From time to time occasionally	1781	53.8	71.9
4 - Not at all	902	27.3	99.1
.a - Missing	29	0.9	100.0
Total	3309	100.0	

E2 I still enjoy the things I used to enjoy: - *hn2_e2_yf_enjoy*

Table 305: 4-months - HADS: I still enjoy the things I used to enjoy

4M - I still enjoy the things I used to enjoy:	No.	Col %	Cum %
1 - Definitely as much	1024	30.9	30.9
2 - Not quite so much	1415	42.8	73.7
3 - Only a little	472	14.3	88.0
4 - Hardly at all	367	11.1	99.1
.a - Missing	31	0.9	100.0
Total	3309	100.0	

E3 I get a sort of frightened feeling as if something awful is about to happen: - *hn2_e3_yf_frightened*

Table 306: 4-months - HADS: I get a sort of frightened feeling as if something awful is about to happen

4M - I get a sort of frightened feeling as if something awful is about to happen	No.	Col %	Cum %
1 - Very definitely and quite badly	202	6.1	6.1
2 - Yes but not to badly	692	20.9	27.0
3 - A little but it does not worry me	950	28.7	55.7
4 - Not at all	1428	43.2	98.9
.a - Missing	37	1.1	100.0
Total	3309	100.0	

E4 I can laugh and see the funny side of things: - *hn2_e4_yf_laugh*

Table 307: 4-months - HADS: I can laugh and see the funny side of things

4M - I can laugh and see the funny side of things:	No.	Col %	Cum %
1 - As much as I always could	2021	61.1	61.1
2 - Not quite so much now	920	27.8	88.9
3 - Definitely not so much now	283	8.6	97.4
4 - Not at all	57	1.7	99.2
.a - Missing	28	0.8	100.0
Total	3309	100.0	

E5 Worrying thoughts go through my mind: - *hn2_e5_yf_worrying***Table 308:** 4-months - HADS: Worrying thoughts go through my mind

4M - Worrying thoughts go through my mind:	No.	Col %	Cum %
1 - A great deal of the time	220	6.6	6.6
2 - A lot of the time	511	15.4	22.1
3 - From time to time but not too often	1325	40.0	62.1
4 - Only occasionally	1186	35.8	98.0
.a - Missing	67	2.0	100.0
Total	3309	100.0	

E6 I feel cheerful: - *hn2_e6_yf_cheerful***Table 309:** 4-months - HADS: I feel cheerful

4M - I feel cheerful:	No.	Col %	Cum %
1 - Not at all	65	2.0	2.0
2 - Not often	335	10.1	12.1
3 - Sometimes	1147	34.7	46.8
4 - Most of the time	1727	52.2	98.9
.a - Missing	35	1.1	100.0
Total	3309	100.0	

E7 I can sit at ease and feel relaxed: - *hn2_e7_yf_at_ease***Table 310:** 4-months - HADS: I can sit at ease and feel relaxed

4M - I can sit at ease and feel relaxed:	No.	Col %	Cum %
1 - Definitely	981	29.6	29.6
2 - Usually	1632	49.3	79.0
3 - Not Often	598	18.1	97.0
4 - Not at all	60	1.8	98.9
.a - Missing	38	1.1	100.0
Total	3309	100.0	

E8 I feel as if I am slowed down: - *hn2_e8_yf_slowed***Table 311:** 4-months - HADS: I feel as if I am slowed down

4M - I feel as if I am slowed down:	No.	Col %	Cum %
1 - Nearly all the time	728	22.0	22.0
2 - Very often	827	25.0	47.0
3 - Sometimes	1341	40.5	87.5
4 - Not at all	381	11.5	99.0
.a - Missing	32	1.0	100.0
Total	3309	100.0	

E9 I get a sort of frightened feeling like 'butterflies' in the stomach: - *hn2_e9_yf_butterflies*

Table 312: 4-months - HADS: I get a sort of frightened feeling like 'butterflies' in the stomach

4M - I get a sort of frightened feeling like butterflies in the stomach:	No.	Col %	Cum %
1 - Not at all	1804	54.5	54.5
2 - Occasionally	1180	35.7	90.2
3 - Quite often	217	6.6	96.7
4 - Very often	70	2.1	98.9
.a - Missing	38	1.1	100.0
Total	3309	100.0	

E10 I have lost interest in my appearance: - *hn2_e10_yf_appearance*

Table 313: 4-months - HADS: I have lost interest in my appearance

4M - I have lost interest in my appearance:	No.	Col %	Cum %
1 - Definitely	134	4.0	4.0
2 - I don't take as much care as I should	451	13.6	17.7
3 - I may not take quite as much care	854	25.8	43.5
4 - I take just as much care as ever	1829	55.3	98.8
.a - Missing	41	1.2	100.0
Total	3309	100.0	

E11 I feel restless as I have to be on the move: - *hn2_e11_yf_restless*

Table 314: 4-months - HADS: I feel restless as I have to be on the move

4M - I feel restless as I have to be on the move:	No.	Col %	Cum %
1 - Very much indeed	169	5.1	5.1
2 - Quite a lot	844	25.5	30.6
3 - Not very much	1302	39.3	70.0
4 - Not at all	957	28.9	98.9
.a - Missing	37	1.1	100.0
Total	3309	100.0	

E12 I look forward with enjoyment to things: - *hn2_e12_yf_enjoyment*

Table 315: 4-months - HADS: I look forward with enjoyment to things

4M - I look forward with enjoyment to things:	No.	Col %	Cum %
1 - As much as I ever did	1540	46.5	46.5
2 - Rather less than I used to	1002	30.3	76.8
3 - Definitely less than I used to	565	17.1	93.9
4 - Hardly at all	156	4.7	98.6
.a - Missing	46	1.4	100.0
Total	3309	100.0	

E13 I get sudden feelings of panic: - *hn2_e13_yf_panic*

Table 316: 4-months - HADS: I get sudden feelings of panic

4M - I get sudden feelings of panic:	No.	Col %	Cum %
1 - Very often indeed	70	2.1	2.1
2 - Quite often	373	11.3	13.4
3 - Not very often	1056	31.9	45.3
4 - Not at all	1763	53.3	98.6
.a - Missing	47	1.4	100.0
Total	3309	100.0	

E14 I can enjoy a good book or radio or TV program: - *hn2_e14_yf_book*

Table 317: 4-months - HADS: I can enjoy a good book or radio or TV program

4M - I can enjoy a good book or radio or TV program:	No.	Col %	Cum %
1 - Often	2106	63.6	63.6
2 - Sometimes	807	24.4	88.0
3 - Not often	223	6.7	94.8
4 - Very seldom	135	4.1	98.9
.a - Missing	38	1.1	100.0
Total	3309	100.0	

4.2.7 Your Diet

F1 In summary, how many servings of fruit do you usually eat, not counting juices? - *hn2_f1_yd_servings_fruit*

Table 318: 4-months - YD: How many servings of fruit do you usually eat, not counting juices?

4M - How many servings of fruit do you usually eat	No.	Col %	Cum %
1 - None	341	10.3	10.3
2 - Less than one per month	150	4.5	14.8
3 - 1-3per month	226	6.8	21.7
4 - 1 per week	253	7.6	29.3
5 - 2-4 per week	647	19.6	48.9
6 - 5-6 per week	230	7.0	55.8
7 - 1 per day	461	13.9	69.7
8 - 2-3 per day	722	21.8	91.6
9 - 4-5 per day	163	4.9	96.5
10 - 6 or more per day	32	1.0	97.5
.a - Missing	84	2.5	100.0
Total	3309	100.0	

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

- *hn2_f2_yd_servings_veg*

Table 319: 4-months - YD: How many servings of vegetables do you usually eat, not counting salad or potatoes?

4M - How many servings of vegetables do you usually eat	No.	Col %	Cum %
1 - None	233	7.0	7.0
2 - Less than one per month	41	1.2	8.3
3 - 1-3per month	92	2.8	11.1
4 - 1 per week	121	3.7	14.7
5 - 2-4 per week	712	21.5	36.2
6 - 5-6 per week	444	13.4	49.7
7 - 1 per day	448	13.5	63.2
8 - 2-3 per day	947	28.6	91.8
9 - 4-5 per day	155	4.7	96.5
10 - 6 or more per day	22	0.7	97.2
.a - Missing	94	2.8	100.0
Total	3309	100.0	

F3 In summary, how often do you eat deep fried food (e.g. French fries, fried chicken, fried fish, fried clams, fried shrimp etc.)? - *hn2_f3_yd_deepfried_food*

Table 320: 4-months - YD: How often do you eat deep fried food?

4M - How often do you eat deep fried food	No.	Col %	Cum %
1 - Never	741	22.4	22.4
2 - Less than once per week	1139	34.4	56.8
3 - Once per week	803	24.3	81.1
4 - 2-4 times per week	499	15.1	96.2
5 - 5-6 times per week	24	0.7	96.9
6 - Daily	14	0.4	97.3
.a - Missing	89	2.7	100.0
Total	3309	100.0	

4.2.8 You and Cancer

The topics covered in the ‘You and Cancer’ questionnaire are based on the ‘Fears of Recurrence’ questionnaire (Humphris and Ozakinci, 2008). Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

G1 I am afraid my cancer may recur - *hn2_g1_yc_cancer_recur*

Table 321: 4-months - YC: I am afraid my cancer may recur

4M - I am afraid that my cancer may recur:	No.	Col %	Cum %
1 - Not at all	305	9.2	9.2
2 - A little	1058	32.0	41.2
3 - Sometimes	1068	32.3	73.5
4 - A lot	572	17.3	90.8
5 - All the time	244	7.4	98.1
.a - Missing	62	1.9	100.0
Total	3309	100.0	

G2 I am worried about the possibility of cancer recurrence - *hn2_g2_yc_recurrence*

Table 322: 4-months - YC: I am worried about the possibility of cancer recurrence

4M - I am worried about the possibility of cancer recurrence:	No.	Col %	Cum %
1 - Not at all	285	8.6	8.6
2 - A little	1089	32.9	41.5
3 - Sometimes	1014	30.6	72.2
4 - A lot	609	18.4	90.6
5 - All the time	218	6.6	97.2
.a - Missing	94	2.8	100.0
Total	3309	100.0	

G3 How often have you worried about the possibility of getting cancer again? - *hn2_g3_yc_how_often*

Table 323: 4-months - YC: How often have you worried about the possibility of getting cancer again?

4M - How often have you worried about the possibility of getting cancer again:	No.	Col %	Cum %
1 - Not at all	219	6.6	6.6
2 - A little	551	16.7	23.3
3 - Sometimes	1549	46.8	70.1
4 - A lot	687	20.8	90.8
5 - All the time	230	7.0	97.8
.a - Missing	73	2.2	100.0
Total	3309	100.0	

G4 I get waves of strong feelings about the cancer coming back - *hn2_g4_yc_strong_feel*

Table 324: 4-months - YC: I get waves of strong feelings about the cancer coming back

4M - I get waves of strong feelings about the cancer coming back:	No.	Col %	Cum %
1 - Not at all	1066	32.2	32.2
2 - A little	818	24.7	56.9
3 - Sometimes	766	23.1	80.1
4 - A lot	401	12.1	92.2
5 - All the time	170	5.1	97.3
.a - Missing	88	2.7	100.0
Total	3309	100.0	

4.2.9 Your Personal Costs

H1a Paid for any kind of medication? - *hn2_h1a_ypc_paid_med*

Table 325: 4-months - YPC: Paid for any kind of medication?

4M - Paid for any kind of medication:	No.	Col %	Cum %
1 - Yes	395	11.9	11.9
2 - No	2162	65.3	77.3
3 - N/A	536	16.2	93.5
.a - Missing	216	6.5	100.0
Total	3309	100.0	

H1b Types of medication - *hn2_h1b_ypc_type_med*

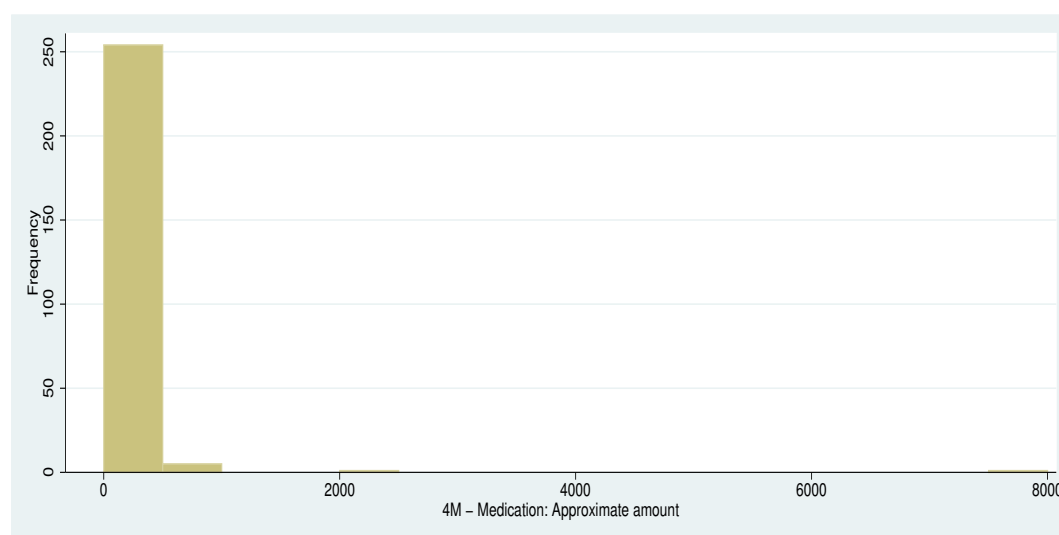
- This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

H1c Paid for any kind of medication, approximate amount - *hn2_h1c_ypc_med_cost*

Descriptives:

- Total valid responses = 261, number of missing values or data check errors = 134

Figure 56: 4-months - YPC: Paid for any kind of treatment, approximate amount



H2a Paid for any kind of treatment - *hn2_h2a_ypc_paid_treat***Table 326:** 4-months - YPC: Paid for any kind of treatment

4M - Paid for any kind of treatment, ie private health care:	No.	Col %	Cum %
1 - Yes	220	6.6	6.6
2 - No	2442	73.8	80.4
3 - N/A	503	15.2	95.6
.a - Missing	144	4.4	100.0
Total	3309	100.0	

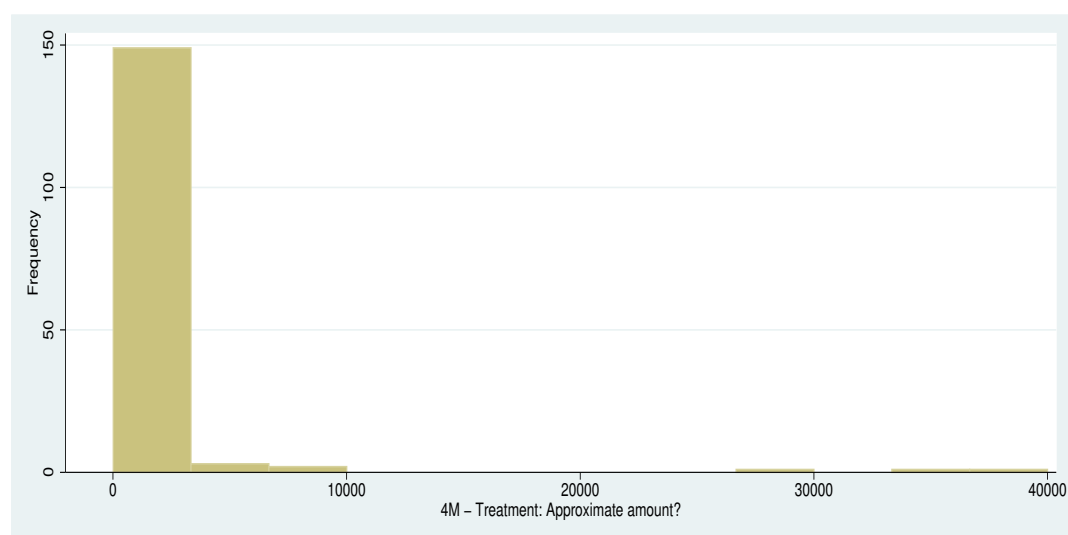
H2b Types of treatment - *hn2_h2b_ypc_type_treat*

- This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

H2c Paid for any kind of treatment, approximate amount - *hn2_h2c_ypc_treat_cost*

Descriptives:

- Total valid responses = 157, number of missing values or data check errors = 63

Figure 57: 4-months - YPC: Paid for any kind of treatment, approximate amount

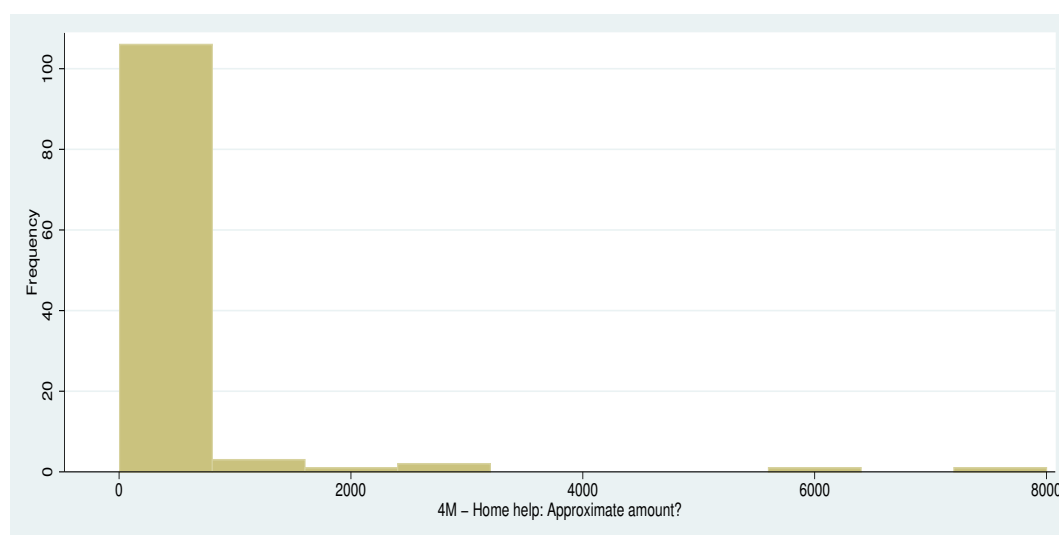
H3a Paid for home help - *hn2_h3a_ypc_home_hlp***Table 327:** 4-months - YPC: Paid for home help

4M - Paid for home help:	No.	Col %	Cum %
1 - Yes	176	5.3	5.3
2 - No	2481	75.0	80.3
3 - N/A	490	14.8	95.1
.a - Missing	162	4.9	100.0
Total	3309	100.0	

H3b Paid for home help, approximate amount - *hn2_h3b_ypc_cost_home_hlp*

Descriptives:

- Total valid responses = 114, number of missing values or data check errors = 62

Figure 58: 4-months - YPC: Paid for home help, approximate amount

H4a Incurred any travel expenses for your hospital/clinic appointments? - *hn2_h4a_ypc_travel_cost*

Table 328: 4-months - YPC: Incurred any travel expenses for your hospital/clinic appointments?

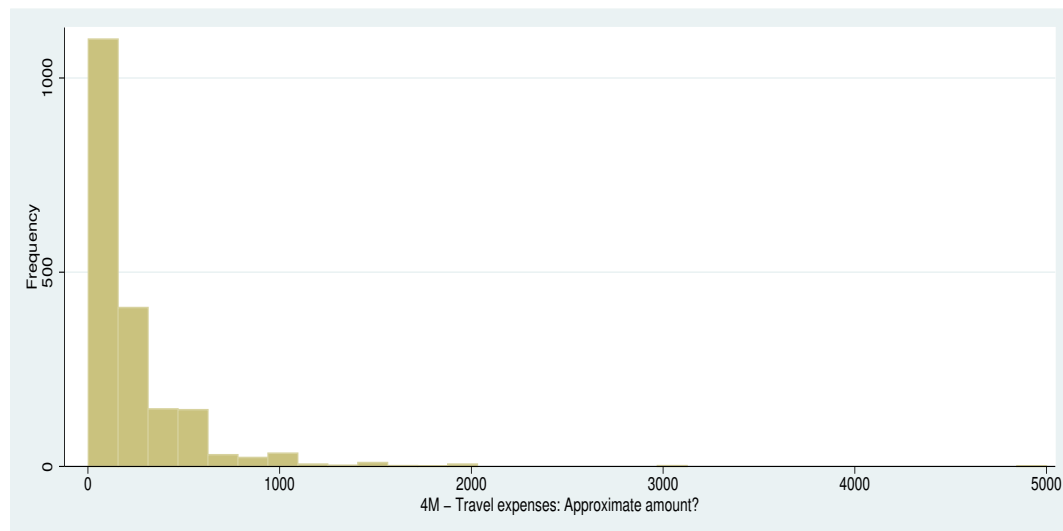
4M - Incurred any travel expenses for your hospital/clinic appointments? (eg tra	No.	Col %	Cum %
1 - Yes	2231	67.4	67.4
2 - No	668	20.2	87.6
3 - N/A	200	6.0	93.7
.a - Missing	210	6.3	100.0
Total	3309	100.0	

H4b Incurred any travel expenses for your hospital/clinic appointments?, approximate amount - *hn2_h4b_ypc_cost_travel*

Descriptives:

- Total valid responses = 1921, number of missing values or data check errors = 310

Figure 59: 4-months - YPC: Incurred any travel expenses for your hospital/clinic appointments?, approximate amount



H5a Incurred any other out-of-pocket expenses - *hn2_h5a_ypc_out_of_pocket***Table 329:** 4-months - YPC: Incurred any other out-of-pocket expenses

4M - Incurred any other out-of-pocket expenses? (e.g. special dietary items, pai	No.	Col %	Cum %
1 - Yes	404	12.2	12.2
2 - No	2255	68.1	80.4
3 - N/A	378	11.4	91.8
.a - Missing	272	8.2	100.0
Total	3309	100.0	

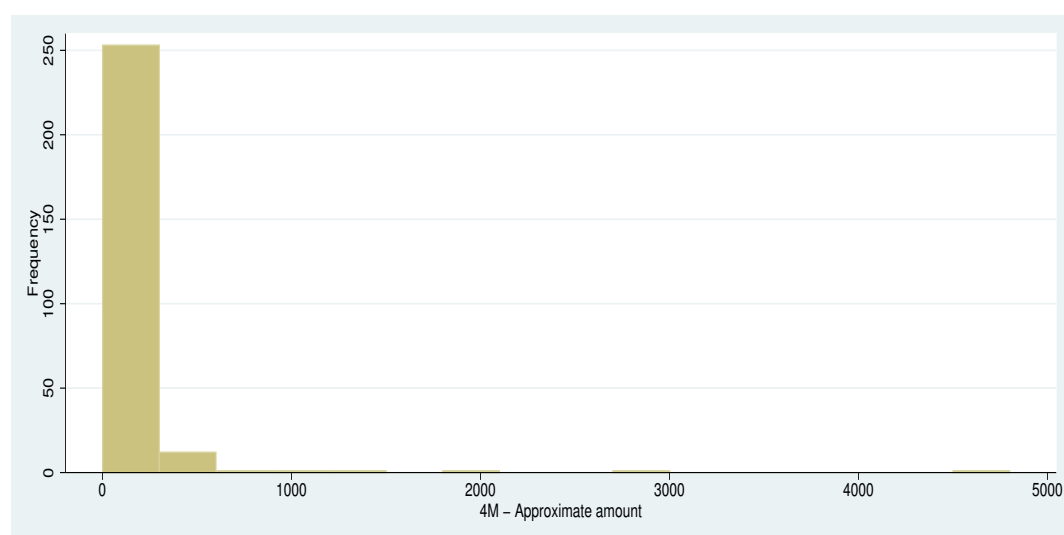
H5b Types of expenditure - *hn2_h5b_ypc_type_expend*

- This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

H5c Incurred any other out-of-pocket expenses, approximate amount - *hn2_h5c_ypc_expend_cost*

Descriptives:

- Total valid responses = 271, number of missing values or data check errors = 133

Figure 60: 4-months - YPC: Incurred any other out-of-pocket expenses, approximate amount

H6a Have you taken time off work because of your illness? - *hn2_h6a_ypc_offwork*

Table 330: 4-months - YPC: Have you taken time off work because of your illness?

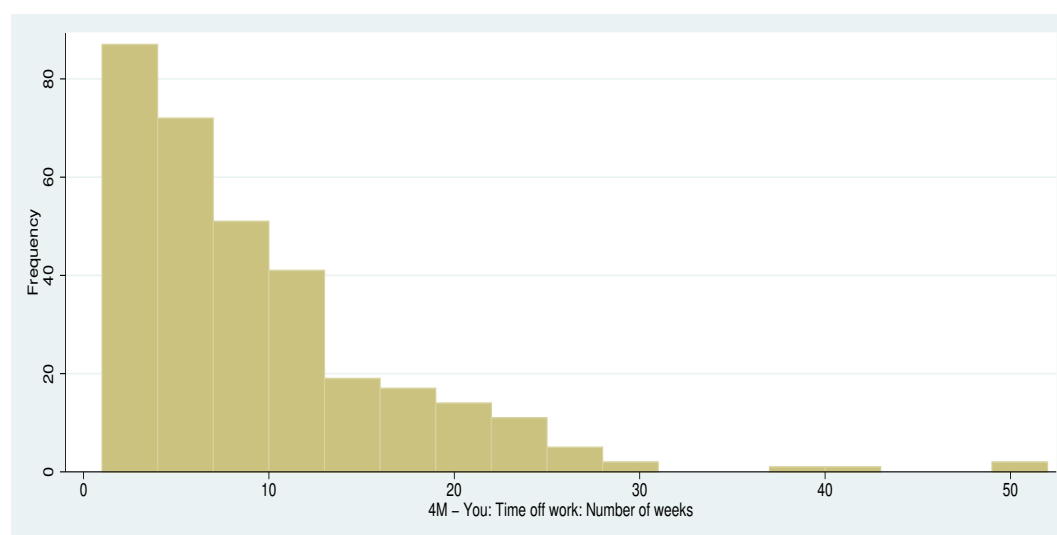
4M - Have you taken time off work because of your illness:	No.	Col %	Cum %
1 - Yes	1410	42.6	42.6
2 - No	977	29.5	72.1
3 - N/A	769	23.2	95.4
.a - Missing	153	4.6	100.0
Total	3309	100.0	

H6b Number of weeks - *hn2_h6b_ypc_offwork_wks*

Descriptives:

- Total valid responses = 323, number of missing values or data check errors = 1087

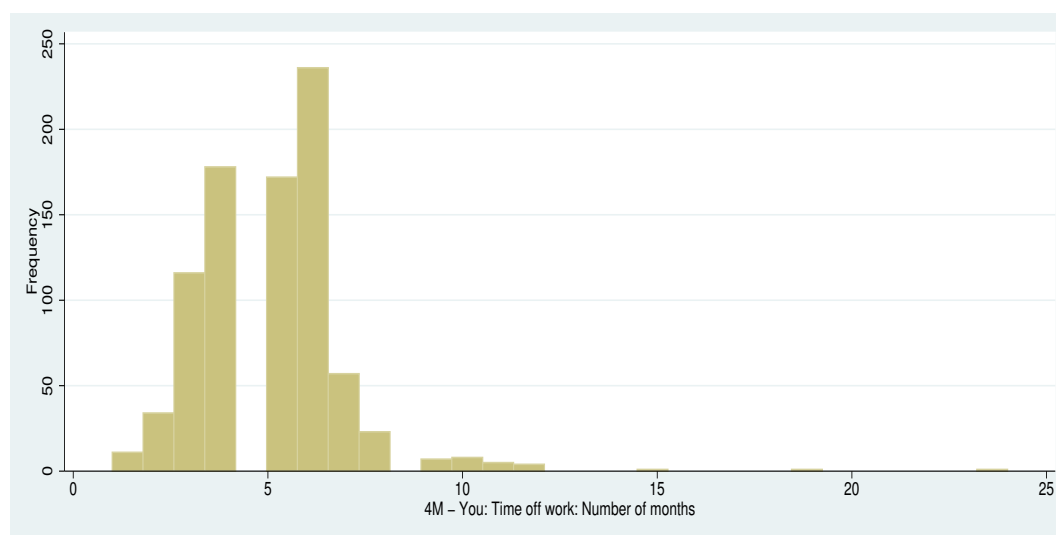
Figure 61: 4-months - YPC: Have you taken time off work because of your illness? Number of weeks



H6c Number of months - *hn2_h6c_ypc_offwork_mths*

Descriptives:

- Total valid responses = 854, number of missing values or data check errors = 556

Figure 62: 4-months - YPC: Have you taken time off work because of your illness? Number of months

H7a Has a member of your immediate family taken time off work because of your illness? -
hn2_h7a_ypc_fam_offwork

Table 331: 4-months - YPC: Has a member of your immediate family taken time off work because of your illness?

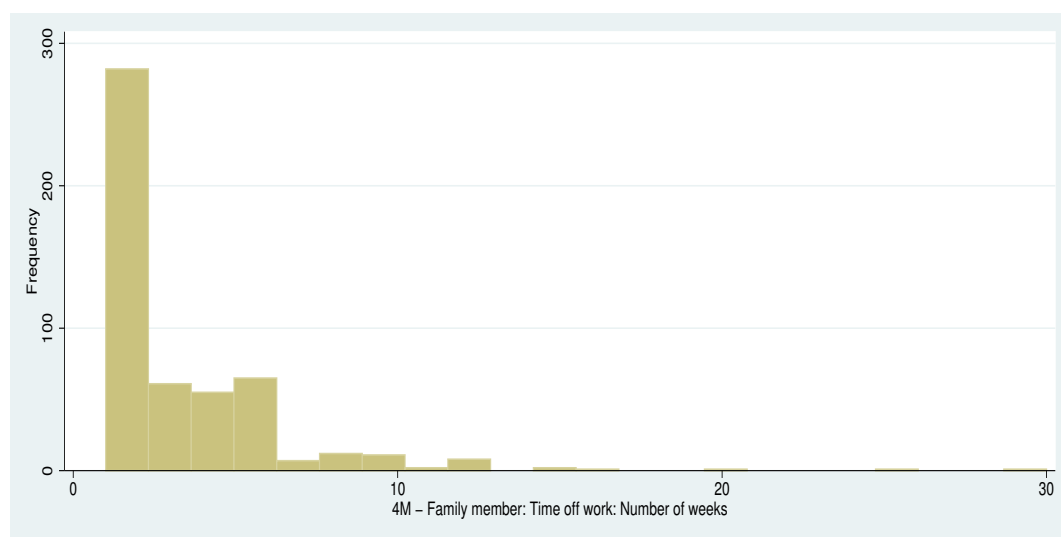
4M - Has a member of your immediate family taken time off work because of your i	No.	Col %	Cum %
1 - Yes	1014	30.6	30.6
2 - No	1616	48.8	79.5
3 - N/A	521	15.7	95.2
.a - Missing	158	4.8	100.0
Total	3309	100.0	

H7b Number of weeks - *hn2_h7b_ypc_fam_offwork_wks*

Descriptives:

- Total valid responses = 509, number of missing values or data check errors = 505

Figure 63: 4-months - YPC: Has a member of your immediate family taken time off work because of your illness? Number of weeks

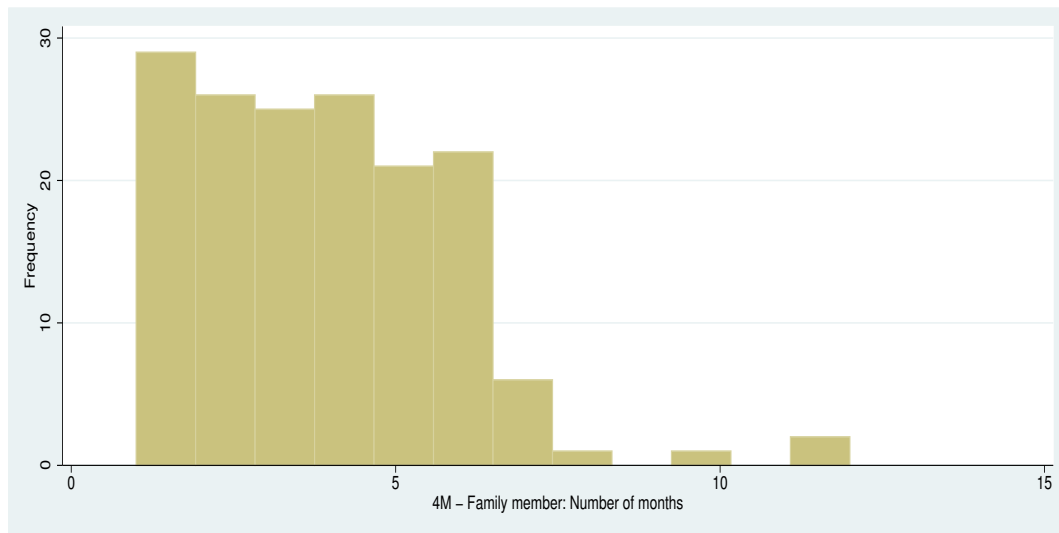


H7c Number of months - *hn2_h7c_ypc_fam_offwork_mths*

Descriptives:

- Total valid responses = 159, number of missing values or data check errors = 855

Figure 64: 4-months - YPC: Has a member of your immediate family taken time off work because of your illness? Number of months



H8a Have you suffered any reduction of income as a result of taking time off work because of your illness? - *hn2_h8a_ypc_reduce_inc*

Table 332: 4-months - YPC: Have you suffered any reduction of income as a result of taking time off work because of your illness?

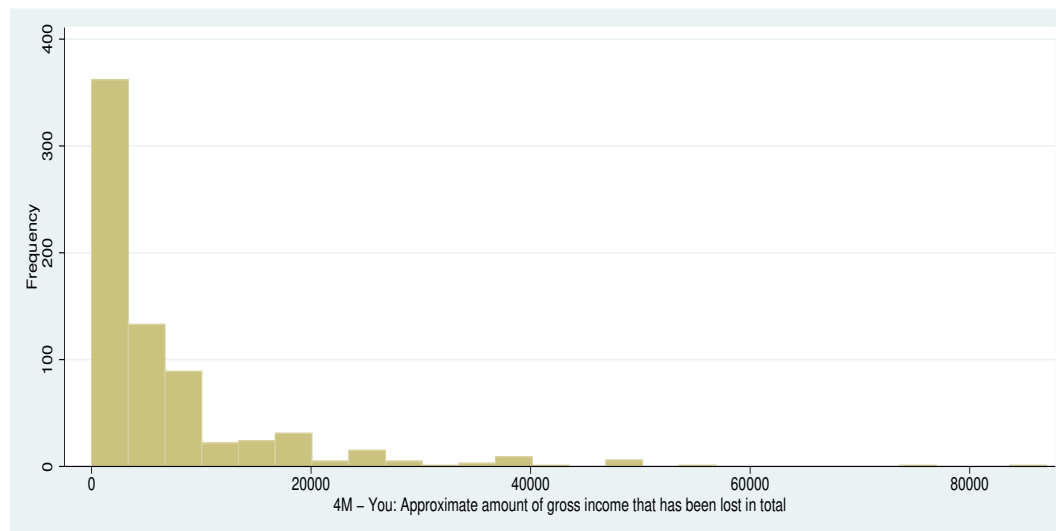
4M - Have you suffered any reduction of income as a result of taking time off wo	No.	Col %	Cum %
1 - Yes	926	28.0	28.0
2 - No	1574	47.6	75.6
3 - N/A	668	20.2	95.7
.a - Missing	141	4.3	100.0
Total	3309	100.0	

H8b Approximate amount of gross income that has been lost in total - *hn2_h8b_ypc_gross_inc*

Descriptives:

- Total valid responses = 709, number of missing values or data check errors = 217

Figure 65: 4-months - YPC: Approximate amount of gross income that has been lost in total.



H9a Has any member of your immediate family suffered any reduction of income as a result of taking time off work because of your illness? - *hn2_h9a_ypc_fam_reduce_inc*

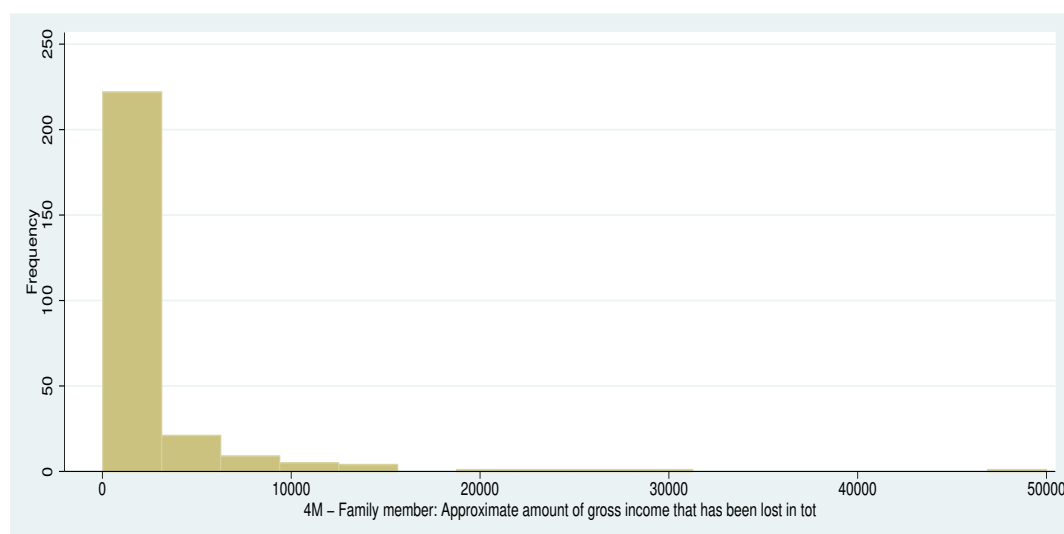
Table 333: 4-months - YPC: Has any member of your immediate family suffered any reduction of income as a result of taking time off work because of your illness?

4M - Has any member of your immediate family suffered any reduction of income as	No.	Col %	Cum %
1 - Yes	416	12.6	12.6
2 - No	2173	65.7	78.2
3 - N/A	559	16.9	95.1
.a - Missing	161	4.9	100.0
Total	3309	100.0	

H9b Approximate amount of gross income that has been lost in total - *hn2_h9b_ypc_fam_gross_inc*
Descriptives:

- Total valid responses = 266, number of missing values or data check errors = 150

Figure 66: 4-months - YPC: Approximate amount of gross income that has been lost in total.



H10a Have you given up work completely because of your illness? - *hn2_h10a_ypc_stop_work*

Table 334: 4-months - YPC: Have you given up work completely because of your illness?

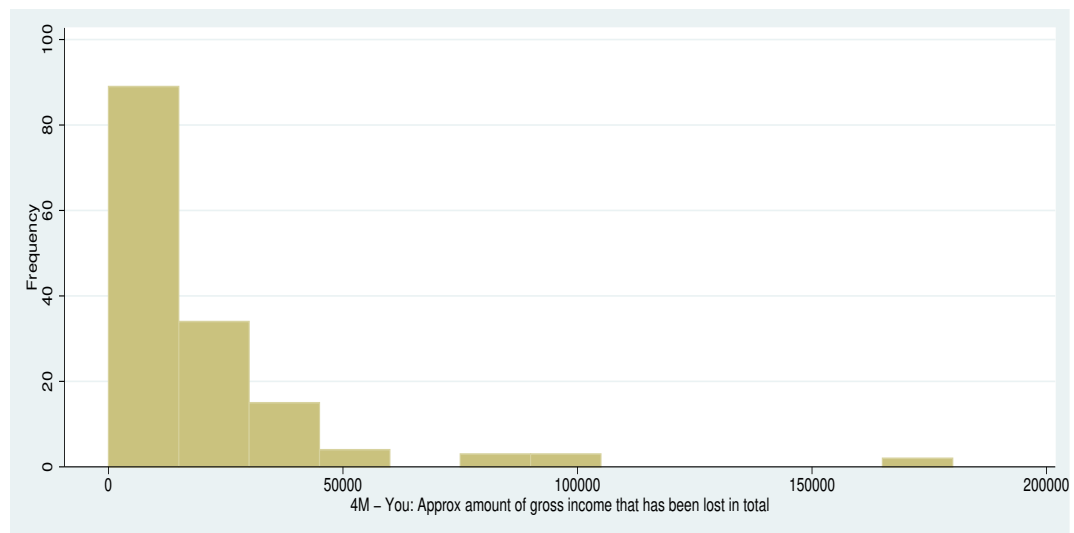
4M - You: Have you given up work completely because of your illness?:	No.	Col %	Cum %
1 - Yes	396	12.0	12.0
2 - No	1817	54.9	66.9
3 - N/A	765	23.1	90.0
.a - Missing	331	10.0	100.0
Total	3309	100.0	

H10b Approximate amount of gross income that has been lost in total - *hn2_h10b_ypc_lost_inc*

Descriptives:

- Total valid responses = 150, number of missing values or data check errors = 246

Figure 67: 4-months - YPC: Approximate amount of gross income that has been lost in total.



H11a Has any member of your immediate family given up work completely because of your illness? - *hn2_h11a_ypc_fam_stop_work*

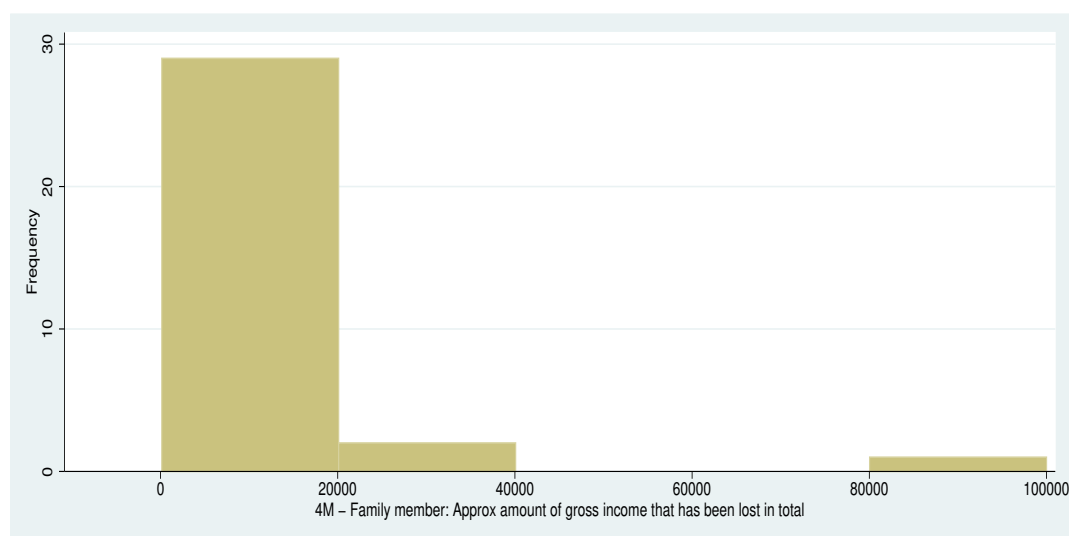
Table 335: 4-months - YPC: Has any member of your immediate family given up work completely because of your illness?

4M - Has any member of your immediate family given up work completely because of	No.	Col %	Cum %
1 - Yes	87	2.6	2.6
2 - No	2385	72.1	74.7
3 - N/A	536	16.2	90.9
.a - Missing	301	9.1	100.0
Total	3309	100.0	

H11b Approximate amount of gross income that has been lost in total - *hn2_h11b_ypc_fam_lost_inc*
Descriptives:

- Total valid responses = 32, number of missing values or data check errors = 55

Figure 68: 4-months - YPC: Approximate amount of gross income that has been lost in total.



H12a Have you run into difficulties with paying the mortgage or rent for the property where you live? - *hn2_h12a_ypc_diffi_mortgage*

Table 336: 4-months - YPC: Have you run into difficulties with paying the mortgage or rent for the property where you live?

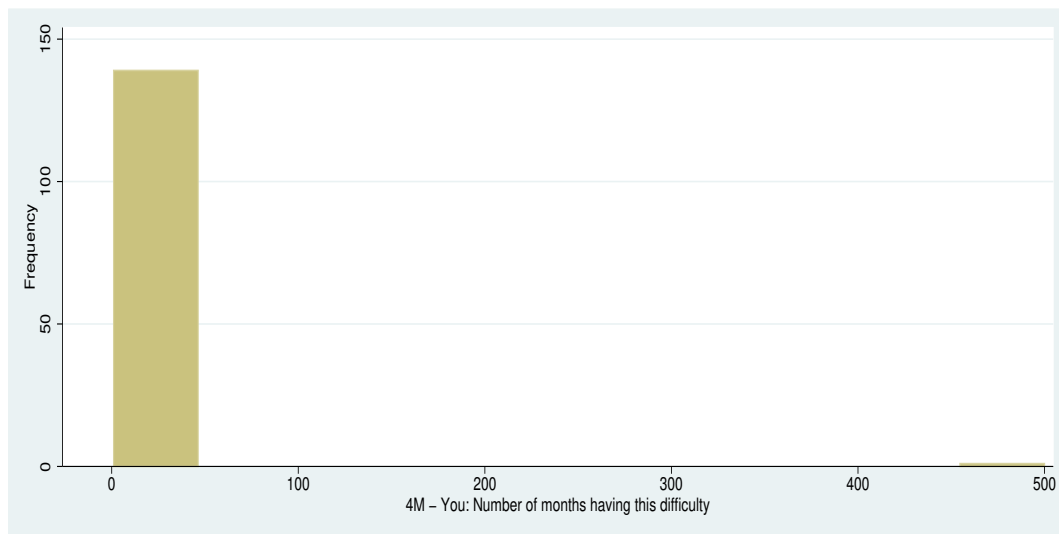
4M - Have you run into difficulties with paying the mortgage or rent for the pro	No.	Col %	Cum %
1 - Yes	237	7.2	7.2
2 - No	2242	67.8	74.9
3 - N/A	536	16.2	91.1
.a - Missing	294	8.9	100.0
Total	3309	100.0	

H12b Number of months having this difficulty - *hn2_h12b_ypc_no_months*

Descriptives:

- Total valid responses = 140, number of missing values or data check errors = 97

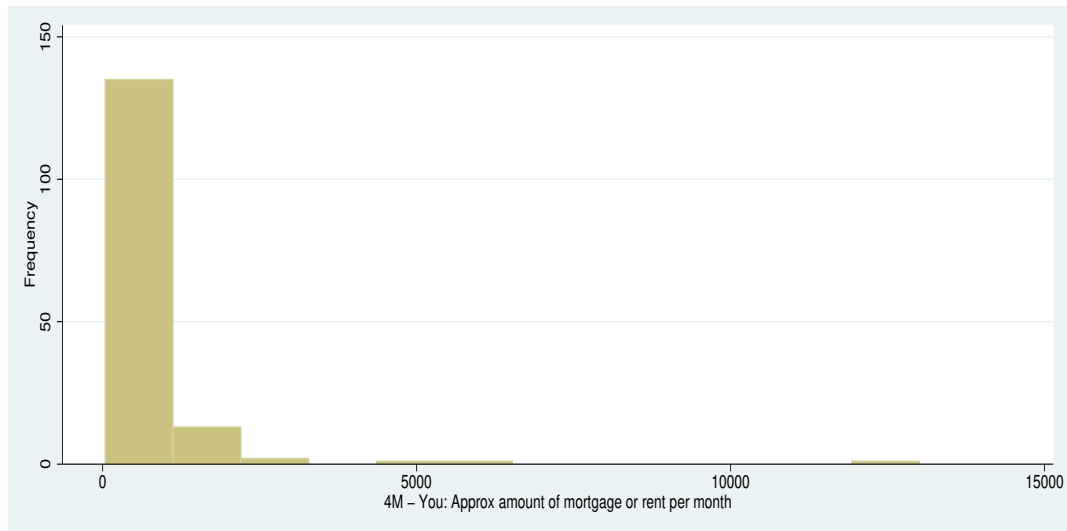
Figure 69: 4-months - YPC: Number of months having this difficulty



H12c Approximate amount of mortgage or rent per month - *hn2_h12c_ypc_mortg_rent_amo*

Descriptives:

- Total valid responses = 153, number of missing values or data check errors = 84

Figure 70: 4-months - YPC: Approximate amount of mortgage or rent per month

4.2.10 Your Quality of Life

The topics covered in the ‘Your Quality of Life’ questionnaire are based on the revised ‘University of Washington (UW) QoL’ questionnaire (Hassan and Weymuller, 1993; Rogers et al., 2002). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

I1 Pain - *hn2_i1_yql_pain***Table 337:** 4-months - UWQoL - Pain

4M - Pain:	No.	Col %	Cum %
1 - I have no pain	78	27.1	27.1
2 - There is mild pain not needing medication	78	27.1	54.2
3 - I have moderate pain(reg medication)	94	32.6	86.8
4 - I have severe pain controlled only by prescription medicine	34	11.8	98.6
5 - I have severe pain not controlled by medication	1	0.3	99.0
.a - Missing	3	1.0	100.0
Total	288	100.0	

I2 Appearance - *hn2_i2_yql_appearance***Table 338:** 4-months - UWQoL - Appearance

4M - Appearance	No.	Col %	Cum %
1 - There is no change in my appearance	67	23.3	23.3
2 - The change in my appearance is minor	151	52.4	75.7
3 - My appearance bothers me but I remain active	58	20.1	95.8
4 - I feel significantly disfigured and limit my activities due to my appearance	10	3.5	99.3
.a - Missing	2	0.7	100.0
Total	288	100.0	

I3 Activity - *hn2_i3_yql_activity***Table 339:** 4-months - UWQoL - A

4M - Activity	No.	Col %	Cum %
1 - I am as active as I have ever been	52	18.1	18.1
2 - There are times when I cannot keep up my old pace but not often	81	28.1	46.2
3 - I am often tired and have slowed down my activities although I still get out	140	48.6	94.8
4 - I donot go out because I donot have the strength	12	4.2	99.0
5 - I am usually in bed or chair and donot leave home	2	0.7	99.7
.a - Missing	1	0.3	100.0
Total	288	100.0	

I4 Recreation - *hn2_i4_yql_recreation***Table 340:** 4-months - UWQoL - Recreation

4M - Recreation	No.	Col %	Cum %
1 - There are no limitations to recreation at home or away from home	64	22.2	22.2
2 - There are a few things I cannot do but I still get out and enjoy life	109	37.8	60.1
3 - There are many times when I wish I could get out more but I am not up to it	86	29.9	89.9
4 - There are severe limitations to what I can do mostly I stay at home and watch TV	25	8.7	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

I5 Swallowing - *hn2_i5_yql_swallowing***Table 341:** 4-months - UWQoL - Swallowing

4M - Swallowing:	No.	Col %	Cum %
1 - I can swallow as well as ever	114	39.6	39.6
2 - I cannot swallow certain solid foods	115	39.9	79.5
3 - I can only swallow liquid food	46	16.0	95.5
4 - I cannot swallow because it goes down the wrong way and chokes me	9	3.1	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

I6 Chewing - *hn2_i6_yql_chewing***Table 342:** 4-months - UWQoL - Chewing

4M - Chewing:	No.	Col %	Cum %
1 - I can chew as well as ever	111	38.5	38.5
2 - I can eat soft solids but cannot chew some foods	133	46.2	84.7
3 - I cannot even chew soft solids	38	13.2	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

I7 Speech - *hn2_i7_yql_speech***Table 343:** 4-months - UWQoL - Speech

4M - Speech:	No.	Col %	Cum %
1 - My speech is the same as always	127	44.1	44.1
2 - I have difficulty with saying some words but I can be understood over the phone	133	46.2	90.3
3 - Only my family and friends can understand me	19	6.6	96.9
4 - Only my family and friends can understand me	4	1.4	98.3
.a - Missing	5	1.7	100.0
Total	288	100.0	

I8 Shoulder - *hn2_i8_yql_shoulder***Table 344:** 4-months - UWQoL - Shoulder

4M - Shoulder	No.	Col %	Cum %
1 - I have no problem with my shoulder	180	62.5	62.5
2 - My shoulder is stiff but it has not affected my activity or strength	51	17.7	80.2
3 - Pain or weakness in my shoulder has caused me to change my work	37	12.8	93.1
4 - I cannot work due to problems with my shoulder	14	4.9	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

I9 Taste - *hn2_i9_yql_taste***Table 345:** 4-months - UWQoL - Taste

4M - Taste:	No.	Col %	Cum %
1 - I can taste food normally	83	28.8	28.8
2 - I can taste most foods normally	55	19.1	47.9
3 - I can taste some foods	109	37.8	85.8
4 - I cannot taste any foods	37	12.8	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

I10 Saliva - *hn2_i10_yql_saliva***Table 346:** 4-months - UWQoL - Saliva

4M - Saliva:	No.	Col %	Cum %
1 - My saliva is of normal consistency	101	35.1	35.1
2 - I have less saliva than normal but it is enough	73	25.3	60.4
3 - I have too little saliva	78	27.1	87.5
4 - I have no saliva	19	6.6	94.1
.a - Missing	17	5.9	100.0
Total	288	100.0	

I11 Mood - *hn2_i11_yql_mood***Table 347:** 4-months - UWQoL - Mood

4M - Mood	No.	Col %	Cum %
1 - My mood is excellent and unaffected by my cancer	60	20.8	20.8
2 - My mood is generally good and only occasionally affected by my cancer	132	45.8	66.7
3 - I am neither in a good mood nor depressed about my cancer	53	18.4	85.1
4 - I am somewhat depressed about my cancer	40	13.9	99.0
5 - I am extremely depressed about my cancer	2	0.7	99.7
.a - Missing	1	0.3	100.0
Total	288	100.0	

I12 Anxiety - *hn2_i12_yql_anxiety***Table 348:** 4-months - UWQoL - Anxiety

4M - Anxiety:	No.	Col %	Cum %
1 - I am not anxious about my cancer	69	24.0	24.0
2 - I am a little anxious about my cancer	170	59.0	83.0
3 - I am anxious about my cancer	39	13.5	96.5
4 - I am very anxious about my cancer	8	2.8	99.3
.a - Missing	2	0.7	100.0
Total	288	100.0	

I13A (1) Which issues have been the most important to you during the past 7 days? - *hn2_i13a_yql_issues*

Table 349: 4-months - UWQoL - (1) Which issues have been the most important to you during the past 7 days?

4M - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
1 - Pain	80	27.8	27.8
2 - Appearance	42	14.6	42.4
3 - Activity	42	14.6	56.9
4 - Recreation	11	3.8	60.8
5 - Swallowing	44	15.3	76.0
6 - Chewing	13	4.5	80.6
7 - Speech	16	5.6	86.1
8 - Shoulder	8	2.8	88.9
9 - Taste	8	2.8	91.7
10 - Saliva	3	1.0	92.7
11 - Mood	7	2.4	95.1
12 - Anxiety	1	0.3	95.5
.a - Missing	13	4.5	100.0
Total	288	100.0	

I13B (2) Which issues have been the most important to you during the past 7 days? - *hn2_i13b_yql_issues*

Table 350: 4-months - UWQoL - (2) Which issues have been the most important to you during the past 7 days?

4M - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
2 - Appearance	13	4.5	4.5
3 - Activity	22	7.6	12.2
4 - Recreation	17	5.9	18.1
5 - Swallowing	44	15.3	33.3
6 - Chewing	30	10.4	43.8
7 - Speech	22	7.6	51.4
8 - Shoulder	15	5.2	56.6
9 - Taste	40	13.9	70.5
10 - Saliva	21	7.3	77.8
11 - Mood	8	2.8	80.6
12 - Anxiety	6	2.1	82.6
.a - Missing	50	17.4	100.0
Total	288	100.0	

I13C (3) Which issues have been the most important to you during the past 7 days? - *hn2_i13c_yql_issues*

Table 351: 4-months - UWQoL - (3) Which issues have been the most important to you during the past 7 days?

4M - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
3 - Activity	1	0.3	0.3
4 - Recreation	6	2.1	2.4
5 - Swallowing	11	3.8	6.3
6 - Chewing	9	3.1	9.4
7 - Speech	16	5.6	14.9
8 - Shoulder	22	7.6	22.6
9 - Taste	28	9.7	32.3
10 - Saliva	63	21.9	54.2
11 - Mood	26	9.0	63.2
12 - Anxiety	26	9.0	72.2
.a - Missing	80	27.8	100.0
Total	288	100.0	

I14 In general, would you say your health-related quality of life during the past 7 days has been: - *hn2_i14_yql_qol_month*

Table 352: 4-months - UWQoL - In general, would you say your health-related quality of life during the past 7 days has been:

4M - Compared to the month before you developed cancer, how would you rate your	No.	Col %	Cum %
1 - Much better	18	6.3	6.3
2 - Somewhat better	32	11.1	17.4
3 - About the same	106	36.8	54.2
4 - Somewhat worse	99	34.4	88.5
5 - Much worse	32	11.1	99.7
.a - Missing	1	0.3	100.0
Total	288	100.0	

I15 In general, would you say your health-related quality of life during the past 7 days has been: - *hn2_i15_yql_qol_7_days*

Table 353: 4-months - UWQoL - In general, would you say your health-related quality of life during the past 7 days has been:

4M - In general, would you say your health-related quality of life during the	No.	Col %	Cum %
1 - Outstanding	5	1.7	1.7
2 - Very good	54	18.8	20.5
3 - Good	89	30.9	51.4
4 - Fair	98	34.0	85.4
5 - Poor	35	12.2	97.6
6 - Very Poor	6	2.1	99.7
.a - Missing	1	0.3	100.0
Total	288	100.0	

I16 Overall quality of life during the past 7 days - *hn2_i16_yql_well_being***Table 354:** 4-months - UWQoL - Overall quality of life during the past 7 days

4M - Considering everything in your life that contributes to your personal well-	No.	Col %	Cum %
1 - Outstanding	7	2.4	2.4
2 - Very good	58	20.1	22.6
3 - Good	91	31.6	54.2
4 - Fair	90	31.3	85.4
5 - Poor	30	10.4	95.8
6 - Very poor	4	1.4	97.2
.a - Missing	8	2.8	100.0
Total	288	100.0	

I17A 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. - *hn2_i17_yql_items*

4.2.11 Difficulties in Your Life

The topics covered in the 'Difficulties in Your Life' questionnaire are based on the 'Social difficulties Inventory (SDI)' questionnaire (Wright et al., 2005). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

J1 Have you had any difficulty maintaining your independence? - *hn2_j1_dyl_independence*

Table 355: 4-months - SDI - Have you had any difficulty maintaining your independence?

4M - Have you had any difficulty maintaining your independence:	No.	Col %	Cum %
1 - No difficulty	190	66.0	66.0
2 - A little	63	21.9	87.8
3 - Quite a bit	27	9.4	97.2
4 - Very much	4	1.4	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

J2 Have you had any difficulty in carrying out your domestic chores? - *hn2_j2_dyl_dom_chores*

Table 356: 4-months - SDI - Have you had any difficulty in carrying out your domestic chores?

4M - Have you had any difficulty in carrying out your domestic chores? (e.g. cle	No.	Col %	Cum %
1 - No difficulty	111	38.5	38.5
2 - A little	114	39.6	78.1
3 - Quite a bit	36	12.5	90.6
4 - Very much	25	8.7	99.3
.a - Missing	2	0.7	100.0
Total	288	100.0	

J3 Have you had any difficulty with managing your own personal care? - *hn2_j3_dyl_personal_care*

Table 357: 4-months - SDI - Have you had any difficulty with managing your own personal care?

4M - Have you had any difficulty with managing your own personal care? (e.g. bat	No.	Col %	Cum %
1 - No difficulty	213	74.0	74.0
2 - A little	60	20.8	94.8
3 - Quite a bit	8	2.8	97.6
4 - Very much	4	1.4	99.0
.a - Missing	3	1.0	100.0
Total	288	100.0	

J4 Have you had any difficulty with looking after those who depend on you? - *hn2_j4_dyl_dependents*

Table 358: 4-months - SDI - Have you had any difficulty with looking after those who depend on you?

4M - Have you had any difficulty with looking after those who depend on you? (e.	No.	Col %	Cum %
1 - No difficulty	204	70.8	70.8
2 - A little	44	15.3	86.1
3 - Quite a bit	13	4.5	90.6
4 - Very much	4	1.4	92.0
.a - Missing	23	8.0	100.0
Total	288	100.0	

J5 Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them? - *hn2_j5_dyl_support*

Table 359: 4-months - SDI - Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?

4M - Have any of those close to you (e.g. partner, children, parents) had any di	No.	Col %	Cum %
1 - No difficulty	225	78.1	78.1
2 - A little	31	10.8	88.9
3 - Quite a bit	7	2.4	91.3
4 - Very much	3	1.0	92.4
.a - Missing	22	7.6	100.0
Total	288	100.0	

J6 Have you had any difficulties with benefits? - *hn2_j6_dyl_benefits*

Table 360: 4-months - SDI - Have you had any difficulties with benefits?

4M - Have you had any difficulties with benefits? (e.g. statutory sick pay, atte	No.	Col %	Cum %
1 - No difficulty	224	77.8	77.8
2 - A little	23	8.0	85.8
3 - Quite a bit	7	2.4	88.2
4 - Very much	15	5.2	93.4
.a - Missing	19	6.6	100.0
Total	288	100.0	

J7 Have you had any financial difficulties? - *hn2_j7_dyl_financial_dif*

Table 361: 4-months - SDI - Have you had any financial difficulties?

4M - Have you had any financial difficulties:	No.	Col %	Cum %
1 - No difficulty	191	66.3	66.3
2 - A little	57	19.8	86.1
3 - Quite a bit	13	4.5	90.6
4 - Very much	13	4.5	95.1
.a - Missing	14	4.9	100.0
Total	288	100.0	

J8 Have you had any difficulties with financial services? - *hn2_j8_dyl_financial_service*

Table 362: 4-months - SDI - Have you had any difficulties with financial services?

4M - Have you had any difficulties with financial services? (e.g. loans, mortgag	No.	Col %	Cum %
1 - No difficulty	241	83.7	83.7
2 - A little	26	9.0	92.7
3 - Quite a bit	3	1.0	93.8
4 - Very much	8	2.8	96.5
.a - Missing	10	3.5	100.0
Total	288	100.0	

J9 Have you had any difficulty concerning your work? - *hn2_j9_dyl_difficulty_work*

Table 363: 4-months - SDI - Have you had any difficulty concerning your work?

4M - Have you had any difficulty concerning your work? (or education if you are	No.	Col %	Cum %
1 - No difficulty	204	70.8	70.8
2 - A little	35	12.2	83.0
3 - Quite a bit	10	3.5	86.5
4 - Very much	12	4.2	90.6
.a - Missing	27	9.4	100.0
Total	288	100.0	

J10 Have you had any difficulty with planning for your own or your family's future? - *hn2_j10_dyl_dif_plan_future*

Table 364: 4-months - SDI - Have you had any difficulty with planning for your own or your family's future?

4M - Have you had any difficulty with planning for your own or your family's fut	No.	Col %	Cum %
1 - No difficulty	225	78.1	78.1
2 - A little	25	8.7	86.8
3 - Quite a bit	11	3.8	90.6
4 - Very much	12	4.2	94.8
.a - Missing	15	5.2	100.0
Total	288	100.0	

J11 Have you had any difficulty communicating with those closest to you? - *hn2_j11_dyl_com_closest*

Table 365: 4-months - SDI - Have you had any difficulty communicating with those closest to you?

4M - Have you had any difficulty communicating with those closest to you? (e.g.	No.	Col %	Cum %
1 - No difficulty	209	72.6	72.6
2 - A little	55	19.1	91.7
3 - Quite a bit	13	4.5	96.2
4 - Very much	4	1.4	97.6
.a - Missing	7	2.4	100.0
Total	288	100.0	

J12 Have you had difficulty communicating with others? - *hn2_j12_dyl_com_others*

Table 366: 4-months - SDI - Have you had difficulty communicating with others?

4M - Have you had difficulty communicating with others? (e.g. friends, neighbour	No.	Col %	Cum %
1 - No difficulty	192	66.7	66.7
2 - A little	72	25.0	91.7
3 - Quite a bit	15	5.2	96.9
4 - Very much	3	1.0	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

J13 Have you had any difficulty concerning sexual matters? - *hn2_j13_dyl_sexual_matters*

Table 367: 4-months - SDI - Have you had any difficulty concerning sexual matters?

4M - Have you had any difficulty concerning sexual matters:	No.	Col %	Cum %
1 - No difficulty	165	57.3	57.3
2 - A little	46	16.0	73.3
3 - Quite a bit	19	6.6	79.9
4 - Very much	28	9.7	89.6
.a - Missing	30	10.4	100.0
Total	288	100.0	

J14 Have you had any difficulty concerning plans to have a family? - *hn2_j14_dyl_dif_having_fam*

Table 368: 4-months - SDI - Have you had any difficulty concerning plans to have a family?

4M - Have you had any difficulty concerning plans to have a family:	No.	Col %	Cum %
1 - No difficulty	219	76.0	76.0
2 - A little	3	1.0	77.1
3 - Quite a bit	4	1.4	78.5
4 - Very much	4	1.4	79.9
.a - Missing	58	20.1	100.0
Total	288	100.0	

J15 Have you had any difficulty concerning your appearance or body image? - *hn2_j15_dyl_body_image*

Table 369: 4-months - SDI - Have you had any difficulty concerning your appearance or body image?

4M - Have you had any difficulty concerning your appearance or body image:	No.	Col %	Cum %
1 - No difficulty	159	55.2	55.2
2 - A little	96	33.3	88.5
3 - Quite a bit	20	6.9	95.5
4 - Very much	7	2.4	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

J16 Have you felt isolated? - *hn2_j16_dyl_felt_isolated*

Table 370: 4-months - SDI - Have you felt isolated?

4M - Have you felt isolated:	No.	Col %	Cum %
1 - No difficulty	158	54.9	54.9
2 - A little	86	29.9	84.7
3 - Quite a bit	26	9.0	93.8
4 - Very much	7	2.4	96.2
.a - Missing	11	3.8	100.0
Total	288	100.0	

J17 Have you had any difficulty with getting around? - *hn2_j17_dyl_mobility*

Table 371: 4-months - SDI - Have you had any difficulty with getting around?

4M - Have you had any difficulty with getting around? (e.g. transport, car parki	No.	Col %	Cum %
1 - No difficulty	187	64.9	64.9
2 - A little	58	20.1	85.1
3 - Quite a bit	25	8.7	93.8
4 - Very much	11	3.8	97.6
.a - Missing	7	2.4	100.0
Total	288	100.0	

J18 Have you had any difficulty with where you live? - *hn2_j18_dyl_dif_live*

Table 372: 4-months - SDI - Have you had any difficulty with where you live?

4M - Have you had any difficulty with where you live? (e.g. space, access, damp,	No.	Col %	Cum %
1 - No difficulty	249	86.5	86.5
2 - A little	17	5.9	92.4
3 - Quite a bit	7	2.4	94.8
4 - Very much	8	2.8	97.6
.a - Missing	7	2.4	100.0
Total	288	100.0	

J19 Have you had any difficulty in carrying out your recreational activities? - *hn2_j19_dyl_dif_recreational*

Table 373: 4-months - SDI - Have you had any difficulty in carrying out your recreational activities?

4M - Have you had any difficulty in carrying out your recreational activities? (No.	Col %	Cum %
1 - No difficulty	115	39.9	39.9
2 - A little	91	31.6	71.5
3 - Quite a bit	46	16.0	87.5
4 - Very much	31	10.8	98.3
.a - Missing	5	1.7	100.0
Total	288	100.0	

J20 Have you had any difficulty with your plans to travel or take a holiday? - *hn2_j20_dyl_dif_travel*

Table 374: 4-months - SDI - Have you had any difficulty with your plans to travel or take a holiday?

4M - Have you had any difficulty with your plans to travel or take a holiday:	No.	Col %	Cum %
1 - No difficulty	133	46.2	46.2
2 - A little	53	18.4	64.6
3 - Quite a bit	45	15.6	80.2
4 - Very much	46	16.0	96.2
.a - Missing	11	3.8	100.0
Total	288	100.0	

J21 Have you had any difficulty with any other area of your everyday life? - *hn2_j21_dyl_dif_other_area*

Table 375: 4-months - SDI - Have you had any difficulty with any other area of your everyday life?

4M - Have you had any difficulty with any other area of your everyday life:	No.	Col %	Cum %
1 - No difficulty	166	57.6	57.6
2 - A little	72	25.0	82.6
3 - Quite a bit	30	10.4	93.1
4 - Very much	6	2.1	95.1
.a - Missing	14	4.9	100.0
Total	288	100.0	

4.2.12 Your Appearance

The topics covered in the ‘Your Appearance’ questionnaire are based on the ‘Derriford Appearance Scale (DAS 24)’ questionnaire (Carr et al., 2005). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.3.2 on page 511.

K1A Is there any aspect of the appearance of your head/neck (however small) that concerns you at all? - *hn2_k1a_ya_appear_hn*

Table 376: 4-months - YA: [hn2 Quests Kq1a] Any aspect of the appearance of your head/neck that concerns you at all?

4M - Is there any aspect of the appearance head/neck that concerns you at all:	No.	Col %	Cum %
1 - Yes	101	35.1	35.1
2 - No	180	62.5	97.6
.a - Missing	7	2.4	100.0
Total	288	100.0	

K2A The aspect of my head/neck about which I am most sensitive or self-conscious is - *hn2_k2a_ya_aspect_hn*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K3A The thing I do not like about the appearance of my head/neck - *hn2_k3a_ya_hn_dont_like*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K4A If you are sensitive or concerned about any other features of - *hn2_k4a_ya_body_dont_like*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K1B How confident do you feel - *hn2_k1b_ya_confident*

Table 377: 4-months - YA: [hn2 Quests Kq1b] How confident do you feel

4M - How confident do you feel:	No.	Col %	Cum %
1 - Not at all	16	5.6	5.6
2 - Slightly	54	18.8	24.3
3 - Moderately	144	50.0	74.3
4 - Extremely	68	23.6	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

K2B How distressed do you get when you see yourself in the mirror/window: - *hn2_k2b_ya_see_yourself_mir*

Table 378: 4-months - YA: [hn2 Quests Kq2b] At present my self-consciousness has an adverse effect on my work:

4M - How distressed do you get when you see yourself in the mirror/window:	No.	Col %	Cum %
1 - Extremely	3	1.0	1.0
2 - Moderately	33	11.5	12.5
3 - A little	95	33.0	45.5
4 - Not at all distressed	154	53.5	99.0
.a - Missing	3	1.0	100.0
Total	288	100.0	

K3B My self-consciousness makes me irritable at home: - *hn2_k3b_ya_selfconscious*

Table 379: 4-months - YA: [hn2 Quests Kq3b] My self-consciousness makes me irritable at home

4M - My self-consciousness makes me irritable at home:	No.	Col %	Cum %
1 - N/A	109	37.8	37.8
2 - Never/Almost never	100	34.7	72.6
3 - Sometimes	65	22.6	95.1
4 - Often	9	3.1	98.3
5 - Almost always	2	0.7	99.0
.a - Missing	3	1.0	100.0
Total	288	100.0	

K4B How hurt do you feel: - *hn2_k4b_ya_hurt_feel*

Table 380: 4-months - YA: [hn2 Quests Kq4b] How hurt do you feel

4M - How hurt do you feel:	No.	Col %	Cum %
1 - Extremely	15	5.2	5.2
2 - Moderately	23	8.0	13.2
3 - Slightly	84	29.2	42.4
4 - Not at all	161	55.9	98.3
.a - Missing	5	1.7	100.0
Total	288	100.0	

K5B At present my self-consciousness has an adverse effect on my work: - *hn2_k5b_ya_selfconscious_work*

Table 381: 4-months - YA: [hn2 Quests Kq5b] At present my self-consciousness has an adverse effect on my work:

4M - At present my self-consciousness has an adverse effect on my work:	No.	Col %	Cum %
1 - Almost always	3	1.0	1.0
2 - Often	9	3.1	4.2
3 - Sometimes	23	8.0	12.2
4 - Never/almost never	46	16.0	28.1
5 - N/A	202	70.1	98.3
.a - Missing	5	1.7	100.0
Total	288	100.0	

K6B How distressed do you get when you go to the beach - *hn2_k6b_ya_distressed_beach*

Table 382: 4-months - YA: [hn2 Quests Kq6b] How distressed do you get when you go to the beach

4M - How distressed do you get when you go to the beach:	No.	Col %	Cum %
1 - N/A	207	71.9	71.9
2 - Not at all	54	18.8	90.6
3 - A little	9	3.1	93.8
4 - Moderately	7	2.4	96.2
5 - Extremely	5	1.7	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

K7B Other people mis-judge me because of the appearance of my head/neck: - *hn2_k7b_ya_misjudge*

Table 383: 4-months - YA: [hn2 Quests Kq7b] Other people mis-judge me because of the appearance of my head/neck:

4M - Other people mis-judge me because of the appearance of my head/neck:	No.	Col %	Cum %
1 - Almost always	3	1.0	1.0
2 - Often	3	1.0	2.1
3 - Sometimes	29	10.1	12.2
4 - Never/almost never	96	33.3	45.5
5 - N/A	150	52.1	97.6
.a - Missing	7	2.4	100.0
Total	288	100.0	

K8B How feminine/masculine do you feel - *hn2_k8b_ya_fem_masc_feel*

Table 384: 4-months - YA: [hn2 Quests Kq8b] How feminine/masculine do you feel

4M - How feminine/masculine do you feel:	No.	Col %	Cum %
1 - Not at all	36	12.5	12.5
2 - Slightly	25	8.7	21.2
3 - Moderately	115	39.9	61.1
4 - Extremely	104	36.1	97.2
.a - Missing	8	2.8	100.0
Total	288	100.0	

K19B How distressed do you get when going to social events - *hn2_k19b_ya_distressed*

Table 385: 4-months - YA: [hn2 Quests Kq19b] How distressed do you get when going to social events

4M - How distressed do you get when going to social events:	No.	Col %	Cum %
1 - N/A	88	30.6	30.6
2 - Not at all	111	38.5	69.1
3 - Moderately	61	21.2	90.3
4 - A fair amount	18	6.3	96.5
5 - Extremely	6	2.1	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

K20B How normal do you feel - *hn2_k20b_ya_normal_feel*

Table 386: 4-months - YA: [hn2 Quests Kq20b] How normal do you feel

4M - How normal do you feel:	No.	Col %	Cum %
1 - Not at all	10	3.5	3.5
2 - Slightly	39	13.5	17.0
3 - Moderately	123	42.7	59.7
4 - Extremely	110	38.2	97.9
.a - Missing	6	2.1	100.0
Total	288	100.0	

K21B At present my self-consciousness has an adverse effect on my sex life: - *hn2_k21b_ya_effect_sex_life*

Table 387: 4-months - YA: [hn2 Quests Kq21b] At present my self-consciousness has an adverse effect on my sex life:

4M - At present my self-consciousness has an adverse effect on my sex life:	No.	Col %	Cum %
1 - Almost always	21	7.3	7.3
2 - Often	14	4.9	12.2
3 - Sometimes	31	10.8	22.9
4 - Never/almost never	68	23.6	46.5
5 - N/A	143	49.7	96.2
.a - Missing	11	3.8	100.0
Total	288	100.0	

K22B Avoid going out of house - *hn2_k22b_ya_avoid_going_out*

Table 388: 4-months - YA: [hn2 Quests Kq22b] Avoid going out of house

4M - Avoid going out of house:	No.	Col %	Cum %
1 - Almost always	5	1.7	1.7
2 - Often	18	6.3	8.0
3 - Sometimes	59	20.5	28.5
4 - Never/almost never	202	70.1	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

K23B How distressed do you get when other people make remarks about the appearance of your head/neck? - *hn2_k23b_ya_remarks_hn*

Table 389: 4-months - YA: [hn2 Quests Kq23b] How distressed do you get when other people make remarks about the appearance of your head/neck?

4M - How distressed do you get when people remark about appearance of your head/	No.	Col %	Cum %
1 - N/A	131	45.5	45.5
2 - Not at all	103	35.8	81.3
3 - Moderately	37	12.8	94.1
4 - A fair amount	9	3.1	97.2
5 - Extremely	4	1.4	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

K24B I avoid going to pubs/restaurants - *hn2_k24b_ya_avoid_pubs*

Table 390: 4-months - YA: [hn2 Quests Kq24b] I avoid going to pubs/restaurants

4M - I avoid going to pubs/restaurants:	No.	Col %	Cum %
1 - Almost always	23	8.0	8.0
2 - Often	14	4.9	12.8
3 - Sometimes	37	12.8	25.7
4 - Never/almost never	125	43.4	69.1
5 - N/A	85	29.5	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

K1C My feature causes me physical pain/discomfort - *hn2_k1c_ya_features*

Table 391: 4-months - YA: [hn2 Quests Kq1c] My feature causes me physical pain/discomfort

4M - My feature causes me physical pain/discomfort:	No.	Col %	Cum %
1 - Never/almost never	183	63.5	63.5
2 - Sometimes	64	22.2	85.8
3 - Often	24	8.3	94.1
4 - Almost always	9	3.1	97.2
.a - Missing	8	2.8	100.0
Total	288	100.0	

K2C My feature limits my physical ability to do the things I want to do: - *hn2_k2c_ya_physical_ability*

Table 392: 4-months - YA: [hn2 Quests Kq2c] My feature limits my physical ability to do the things I want to do:

4M - My feature limits my physical ability to do the things I want to do:	No.	Col %	Cum %
1 - Almost always	13	4.5	4.5
2 - Often	16	5.6	10.1
3 - Sometimes	59	20.5	30.6
4 - Never/almost never	191	66.3	96.9
.a - Missing	9	3.1	100.0
Total	288	100.0	

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? - *hn2_k3c_ya_disfigurement*

Table 393: 4-months - YA: [hn2 Quests Kq3c] To what extent is any disfigurement or change to your appearance as a result of your cancer or its treatment noticeable to other people?

4M - To what extent is any disfigurement or change to your appearance as a result	No.	Col %	Cum %
1 - Not at all noticable	100	34.7	34.7
2 - 2	44	15.3	50.0
3 - 3	39	13.5	63.5
4 - Moderately noticable	55	19.1	82.6
5 - 5	18	6.3	88.9
6 - 6	12	4.2	93.1
7 - Extremely noticable	16	5.6	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

K4C How much will your treatment change the way you look - *hn2_k5c_ya_treatment*

Table 394: 4-months - YA: [hn2 Quests Kq5c] How much will your treatment change the way you look

4M - How much will your treatment change the way you look	No.	Col %	Cum %
1 - Not at all	94	32.6	32.6
2 - 2	89	30.9	63.5
3 - 3	62	21.5	85.1
4 - 4	22	7.6	92.7
5 - Very much	18	6.3	99.0
.a - Missing	3	1.0	100.0
Total	288	100.0	

K6C How much does this bother you - *hn2_k6c_ya_bother_you*

Table 395: 4-months - YA: [hn2 Quests Kq6c] How much does this bother you

4M - How much does this bother you	No.	Col %	Cum %
1 - Not at all	146	50.7	50.7
2 - 2	64	22.2	72.9
3 - 3	42	14.6	87.5
4 - 4	20	6.9	94.4
5 - Very much so	12	4.2	98.6
.a - Missing	4	1.4	100.0
Total	288	100.0	

5 Stage 3 - 12-Months

5.1 Data Capture Form

5.1.1 Section A - Basic Data

In order to protect the confidentiality of participants the following date variables are not available. Variables have been derived (see the appropriate ‘Derived variables’ sections) which describe participants’ age at events. These variables can be used to define timelines for participants.

1 Date of data collection (*hn3_na1_cb_date*) - please use ‘Days from consent to 12M DCF data collection’ (*hn3_dv_dcf_age*)

5-A TNM date (*hn3_nb5a_cb_tnm_date*) - please use ‘Days from consent to most recent TNM staging’ (*hn3_dv_tnm_age*)

10 Procedure or treatment start date (*hn3_nb10_cb_start_date*) - please use ‘Days from consent to start of further treatment’ (*hn3_dv_start_age*)

5.1.2 Section B - Treatment**1a Actual cancer plan intent 1***hn3_nbl_cb_plan_intent_1*

- Data check
- Used to derive
- Descriptives

Table 396: 12-months - Actual cancer plan intent 1

12M - Plan Intent 1:	No.	Col %	Cum %
1 - Curative	4614	90.0	90.0
2 - Palliative	263	5.1	95.1
3 - Supportive	186	3.6	98.8
4 - No Specific anti-cancer	6	0.1	98.9
.a - Missing	58	1.1	100.0
Total	5127	100.0	

Notes:

1b Actual cancer plan intent 2*hn3_nb1_cb_plan_intent_2*

- Data check
- Used to derive
- Descriptives

Table 397: 12-months - Actual cancer plan intent 2

12M - Plan Intent 2 (4M and 12M only):	No.	Col %	Cum %
2 - Palliative	34	0.7	0.7
3 - Supportive	52	1.0	1.7
5 - N/A	5041	98.3	100.0
Total	5127	100.0	

Notes:

1c Actual cancer plan intent 3*hn3_nb1_cb_plan_intent_3*

- Data check
- Used to derive
- Descriptives

Table 398: 12-months - Actual cancer plan intent 3

12M - Plan Intent 3 (4M and 12M only):	No.	Col %	Cum %
3 - Supportive	1	0.0	0.0
5 - N/A	5126	100.0	100.0
Total	5127	100.0	

Notes:

2 Further cancer treatment type

hn3_nb2_cb

- Data check
- Used to derive
- Descriptives

Table 399: 12-months - Further cancer treatment type

	No.	Col %
12M - Surgery(Primary Site):		
1 - Yes	113	100.0
Total	113	100.0
12M - Surgery(Neck):		
1 - Yes	214	100.0
Total	214	100.0
12M - Teletherapy:		
1 - Yes	132	100.0
Total	132	100.0
12M - Chemotherapy:		
1 - Yes	96	100.0
Total	96	100.0
12M - Hormone therapy:		
1 - Yes	5	100.0
Total	5	100.0
12M - Specialist Paliative:		
1 - Yes	222	100.0
Total	222	100.0
12M - Brachytherapy:		
1 - Yes	1	100.0
Total	1	100.0
12M - Biological:		
1 - Yes	19	100.0
Total	19	100.0
12M - Other:		
1 - Yes	212	100.0
Total	212	100.0
12M - Active Monitoring:		
1 - Yes	4655	100.0
Total	4655	100.0
12M - Combined chemoradiotherapy:		
1 - Yes	33	100.0
Total	33	100.0
12M - Reconstruction with free flap:		
1 - Yes	28	100.0
Total	28	100.0
12M - Laser surgery:		
1 - Yes	12	100.0
Total	12	100.0

Notes:

3 Treatment type sequence*hn3_nb3_cb_sequence*

- **Data check**
 - **Used to derive**
 - **Descriptives:**
-

Notes: – Data for this field are currently undergoing further processing. A cleaned version of this variable will be available in a future data release.

4 Co-morbidity*hn3_nb4_cb_comorb_index*

- **Data check**
- **Used to derive**
- **Descriptives**

Table 400: 12-months - Co-morbidity

12M - Co-morb index:	No.	Col %	Cum %
1 - No co-morbidity	1982	38.7	38.7
2 - Mild discompensation	1497	29.2	67.9
3 - Moderate discompensation	819	16.0	83.8
4 - Severe discompensation	319	6.2	90.1
5 - Unknown	351	6.8	96.9
.a - Missing	159	3.1	100.0
Total	5127	100.0	

Notes:

5b Most recent tumour staging -

- **Data check**
 - **Used to derive**
 - Most recent cancer stage - (hn3_TNM_stage)
 - **Descriptives:**
-

Notes:

11 Was radiotherapy completed?*hn3_nb11_cb_radiotherapy*

- Data check
- Used to derive
- Descriptives

Table 401: 12-months - Was radiotherapy completed?

12M - Was the initial/prescribed course of radioth treatmt completed:	No.	Col %	Cum %
1 - Yes	3767	73.5	73.5
2 - No	48	0.9	74.4
4 - Not Applicable	1297	25.3	99.7
.a - Missing	15	0.3	100.0
Total	5127	100.0	

Notes:

11a Radiotherapy incomplete reason*hn3_nb11a_cb_radio_incomp*

- Data check
- Used to derive
- Descriptives

Table 402: 12-months - Radiotherapy incomplete - reason

12M - Radioth not completed reason:	No.	Col %	Cum %
1 - Toxicity/side effects	18	0.4	0.4
2 - Altered treatment plan	9	0.2	0.5
3 - Patient choice	16	0.3	0.8
4 - Other	4	0.1	0.9
.a - Missing	5080	99.1	100.0
Total	5127	100.0	

Notes:

12 Was chemotherapy completed?*hn3_nb12_cb_chemotherapy*

- Data check
- Used to derive
- Descriptives

Table 403: 12-months - Was chemotherapy completed?

12M - Was the initial/prescribed course of chemotherapy treatment completed:	No.	Col %	Cum %
1 - Yes	1822	35.5	35.5
2 - No	260	5.1	40.6
3 - Ongoing	2	0.0	40.6
4 - Not Applicable	3025	59.0	99.6
.a - Missing	18	0.4	100.0
Total	5127	100.0	

Notes:

12a Chemotherapy incomplete reason*hn3_nb12a_cb_chemo_incomp*

- Data checkptives
- Used to derive
- Descriptives

Table 404: 12-months - Chemotherapy incomplete - reason

12M - Radioth not completed reason:	No.	Col %	Cum %
1 - Toxicity/side effects	208	4.1	4.1
2 - Altered treatment plan	17	0.3	4.4
3 - Patient choice	12	0.2	4.6
4 - Other	21	0.4	5.0
.a - Missing	4869	95.0	100.0
Total	5127	100.0	

Notes:

13 PEG*hn3_nb13_cb_peg*

- **Data check**
- **Used to derive**
- **Descriptives**

Table 405: 12-months - PEG

12M - Does the patient have peg:	No.	Col %	Cum %
1 - Yes	568	11.1	11.1
2 - No	4417	86.2	97.2
.a - Missing	142	2.8	100.0
Total	5127	100.0	

Notes:

14 How much feeding through PEG*hn3_nb14_cb_feeding_peg*

- **Data check**
 - If ‘PEG’ = yes & ‘How much feeding through PEG’ = missing
- **Used to derive**
- **Descriptives**

Table 406: 12-months - How much feeding through PEG

12M - Approximately how much feeding is through peg:	No.	Col %	Cum %
1 - None	73	1.4	1.4
2 - Less than 20%	47	0.9	2.3
3 - 20-80%	147	2.9	5.2
4 - Greater than 80%	234	4.6	9.8
.a - Missing	4626	90.2	100.0
Total	5127	100.0	

Notes:

15 Tracheostomy*hn3_nb15_cb_tracheostomy*

- Data check
- Used to derive
- Descriptives

Table 407: 12-months - Tracheostomy

12M - Does the patient have a tracheostomy:	No.	Col %	Cum %
1 - Yes	206	4.0	4.0
2 - No	4827	94.1	98.2
.a - Missing	94	1.8	100.0
Total	5127	100.0	

Notes:

16a Tumour recurrence*hn3_nb16a_cb_recurrence*

- Data check
- Used to derive
- Descriptives

Table 408: 12-months - Tumour recurrence

12M - Has there been tumour recurrence:	No.	Col %	Cum %
1 - Yes	482	9.4	9.4
2 - No	4400	85.8	95.2
3 - NA	157	3.1	98.3
.a - Missing	88	1.7	100.0
Total	5127	100.0	

Notes:

16 Tumour recurrence stage -• **Data check**

– If ‘Tumour recurrence’ = yes & ‘Tumour recurrence stage’ = missing

• **Used to derive**• **Descriptives****Table 409:** 12-months - Tumour recurrence T, N & M codes

12M - T	No.	Col %	Cum %
0	17	0.3	0.3
1	10	0.2	0.5
1a	1	0.0	0.5
2	36	0.7	1.2
2a	2	0.0	1.3
3	22	0.4	1.7
4	38	0.7	2.5
4a	18	0.4	2.8
4b	6	0.1	2.9
NK	1	0.0	2.9
pT1	2	0.0	3.0
pT1b	1	0.0	3.0
pT3	2	0.0	3.0
pT4	1	0.0	3.1
pT4a	8	0.2	3.2
x	12	0.2	3.5
	4950	96.5	100.0
Total	5127	100.0	

12M - N	No.	Col %	Cum %
0	73	1.4	1.4
1	16	0.3	1.7
2	12	0.2	2.0
2a	2	0.0	2.0
2b	41	0.8	2.8
2c	12	0.2	3.0
3	5	0.1	3.1
NK	1	0.0	3.2
pN0	4	0.1	3.2
pN1	2	0.0	3.3
pN2a	1	0.0	3.3
pN2b	2	0.0	3.3
pN2c	1	0.0	3.4
pT2a	1	0.0	3.4
pT2c	1	0.0	3.4
x	8	0.2	3.5
ypN1	1	0.0	3.6
ypN2b	1	0.0	3.6
ypN2c	1	0.0	3.6
	4942	96.4	100.0
Total	5127	100.0	

12M - M	No.	Col %	Cum %
0	116	2.3	2.3
1	61	1.2	3.5
1a	1	0.0	3.5
1b	1	0.0	3.5
X	1	0.0	3.5
x	17	0.3	3.8
	4930	96.2	100.0
Total	5127	100.0	

Notes:

5.1.3 Section C - Other

1 Patient trial status

hn3_nc1_cb_pts_trial_status

Table 410: 12-months - Patient trial status

12M - Patient trial status:	No.	Col %	Cum %
1 - Eligible, entered	377	7.4	7.4
2 - Eligible, declined	36	0.7	8.1
3 - Eligible, not approached	89	1.7	9.8
4 - Ineligible	863	16.8	26.6
5 - Not applicable	3491	68.1	94.7
.a - Missing	271	5.3	100.0
Total	5127	100.0	

Notes:

2 Comments*hn3_nc2_cb_comments*

Notes: – This is a free text field and will not be documented. Data for this variable are available through a standard data request.

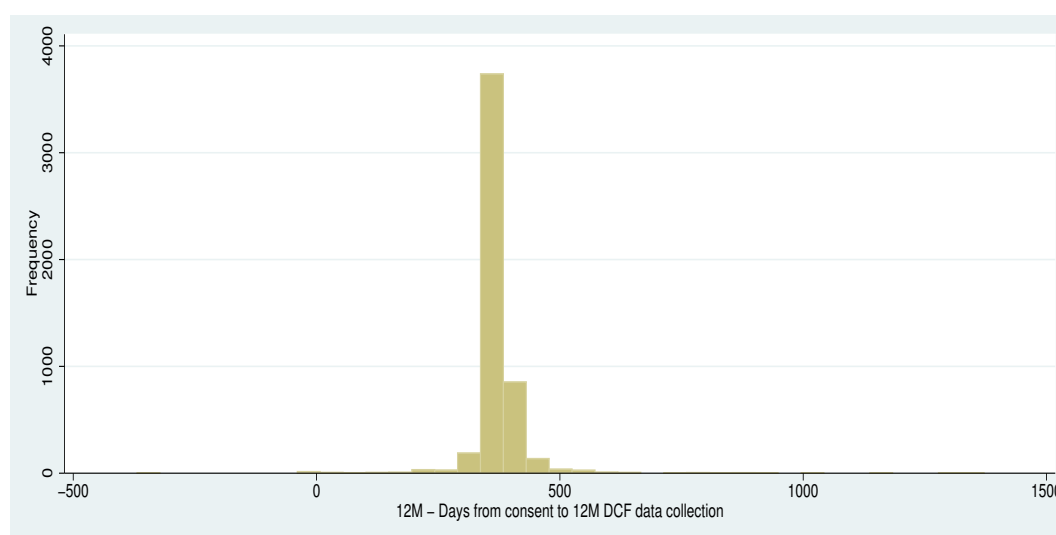
5.1.4 Derived variables

Variables derived from the 12-month Data Capture Forms.

1. Days from consent to 12M DCF data collection

- *Date of 12M DCF data collection (hn3_na1_cb_date) - Date of birth (hn1_na2_cb_dob)*
- Stata code to derive variable:
 - `gen hn3_dv_dcf_age = hn3_na1_cb_date - hn1_na2_cb_dob`
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 5127, number of missing values or data check errors = 0

Figure 71: Days from consent to 12M DCF data collection

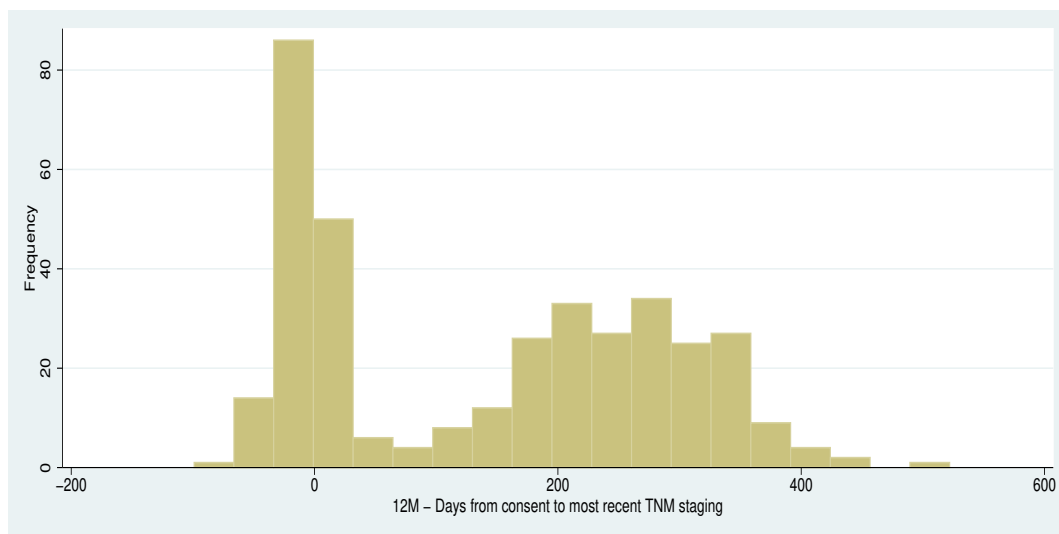


Notes:

2. Days from consent to most recent TNM staging

- *Date of most recent TNM staging (hn3_nb5a_cb_tnm_date) - Date of birth (hn1_na2_cb_dob)*
- Stata code to derive variable:
 - `gen hn3_dv_tnm_age = hn3_nb5a_cb_tnm_date - hn1_na2_cb_dob`
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 369, number of missing values or data check errors = 4758

Figure 72: Days from consent to most recent TNM staging

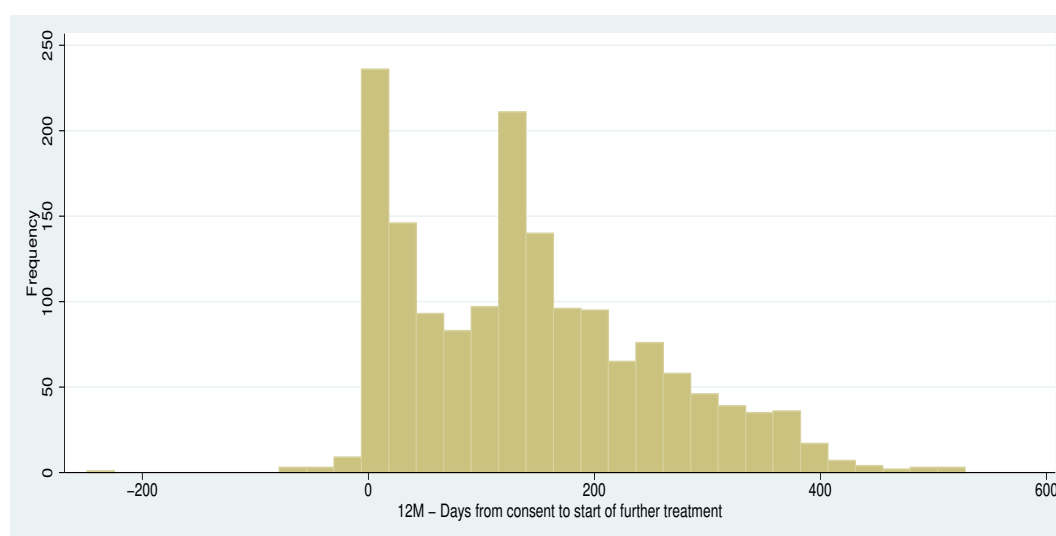


Notes:

3. Days from consent to start of further treatment

- Date of start of treatment (*hn3_nb10_cb_start_date*) - Date of birth (*hn1_na2_cb_dob*)
- Stata code to derive variable:
 - `gen hn3_dv_start_age = hn3_nb10_cb_start_date - hn1_na2_cb_dob`
- Used to derive
- Descriptives:
 - Total valid responses = 1604, number of missing values or data check errors = 3523

Figure 73: Days from consent to start of further treatment



Notes:

4. Most recent cancer staging

hn3_TNM_stage

- Using most recent T, N and M data

Table 411: 12-months - Most recent cancer staging

12M - TNM staging	No.	Col %	Cum %
1 - I	40	0.8	0.8
2 - II	41	0.8	1.6
3 - IIa	1	0.0	1.6
5 - III	34	0.7	2.3
6 - IVa	114	2.2	4.5
7 - IVb	17	0.3	4.8
8 - IVc	47	0.9	5.7
.e - Incomplete T and/or N and/or M codes	4663	90.9	96.7
.f - TNM combination unacceptable	24	0.5	97.2
.g - Other	146	2.8	100.0
Total	5127	100.0	

- Notes:**
- Tumour staging was derived using the ‘TNM staging of head and neck cancer and neck dissection classification’ Deschler and Day (2008).
 - The ‘Other’ category refers to patients with either an unknown primary tumour site, no valid ICD code or with a valid ICD code which is not currently allocated to a tumour site group. Refer to *hn1_ICD_group* for more details.

5. Simplified - Most recent cancer staging

hn3_TNM_stage2

Using most recent T, N and M data

Table 412: 12-months - Simplified - Most recent cancer staging

12M - Simplified TNM staging	No.	Col %	Cum %
1 - I	132	2.6	2.6
2 - II	42	0.8	3.4
3 - III	34	0.7	4.1
4 - IV	185	3.6	7.7
.e - Incomplete T and/or N and/or M codes	4566	89.1	96.7
.f - TNM combination unacceptable	22	0.4	97.2
.g - Other	146	2.8	100.0
Total	5127	100.0	

- Notes:**
- The simplified tumour staging was derived using a modified version of the ‘TNM staging of head and neck cancer and neck dissection classification’ Deschler and Day (2008). See Appendix B for details.
 - The ‘Other’ category refers to patients with either an unknown primary tumour site, no valid ICD code or with a valid ICD code which is not currently allocated to a tumour site group. Refer to *hn1_ICD_group* for more details.

5.2 Questionnaires

5.2.1 About You

The topics covered in the 'About You' questionnaire are:

1. Education and occupation - (Lagiou et al., 2009)
2. Income - (Benzeval et al., 2009)
3. EQ5D - (Brooks et al., 2003)
4. Smoking and alcohol - (The Million Women Study Collaborative Group, 1999; Sitas et al., 2013)

Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

In order to protect the confidentiality of participants the following date variables are not available. Variables have been derived (see the appropriate ‘Derived variables’ sections) which describe participants’ age at events. These variables can be used to define timelines for participants.

A1 Date of completion (*hn3_a1_ay_date*) - Please use ‘Age at completion of 12M AY (days)’ (*hn3_dv_ay_age*)

A2 Date of birth (*hn3_a2_ay_dob*) - Please use ‘Age at completion of 12M AY (days)’ (*hn3_dv_ay_age*)

A4a Self-reported weight (kg)*hn3_a4a_ay_kg_weight***A4b1 Self-reported weight (stone)***hn3_a4b1_ay_stone_weight***A4b2 Self-reported weight (lbs)***hn3_a4b2_ay_lbs_weight*

Notes: • These variables have not been documented. Please refer to the derived variable which combines these variables in a single variable for ‘weight’ - *hn3_dv_weight_kg*.

A5 Marital status*hn3_a5_ay_marital_status*

- Categories
 - 1 *Single*
 - 2 *Widowed*
 - 3 *Separated*
 - 4 *Married*
 - 5 *Divorced*
 - 6 *Living with a partner*
- Quality control
- Used to derive

Table 413: 12-months - AY: Marital status

12M - Are you currently:	No.	Col %	Cum %
1 - Single	318	11.3	11.3
2 - Widowed	209	7.4	18.8
3 - Separated	52	1.9	20.6
4 - Married	1651	58.8	79.5
5 - Divorced	264	9.4	88.9
6 - Living with a partner	266	9.5	98.4
.a - Missing	46	1.6	100.0
Total	2806	100.0	

Notes:

A8a [HN1 Quests Aq8a] Tobacco 4/12 mnth*hn3_a8_ay_tobacco4mnth*

- Quality control
- Used to derive:
- Descriptives:

Table 414: 12-months - AY: [HN1 Quests Aq8a] Tobacco 4/12 mnth

12M - Tobacco 4 mnth	No.	Col %	Cum %
1 - Current User	269	9.6	9.6
2 - Former or Never	1931	68.8	78.4
.a - Missing	606	21.6	100.0
Total	2806	100.0	

Notes:

A13a In a typical week how many days do you drink alcohol?*hn3_a13a_ay_drink_days*

- Quality control
- Used to derive

Table 415: 12-months - AY: In a typical week how many days do you drink alcohol?

12M - In a typical week how many days do you drink alcohol?	No.	Col %	Cum %
0	184	6.6	6.6
1	287	10.2	16.8
2	298	10.6	27.4
3	262	9.3	36.7
4	160	5.7	42.4
5	181	6.5	48.9
6	68	2.4	51.3
7	271	9.7	61.0
.a	1095	39.0	100.0
Total	2806	100.0	

A13b 'None' ticked - *hn3_a13b_ay_drink_days***Table 416:** 12-months - AY: None ticked

12M - If none, tick the box and go to question A17	No.	Col %	Cum %
1 - Ticked	915	32.6	32.6
.a - Missing	1891	67.4	100.0
Total	2806	100.0	

Notes:

A15 About how many bottles of wine, spirits and pints of beers did you drink on average each week?**Table 417:** 12-months - AY: About how many bottles of wine, spirits and pints of beers did you drink on average each week?a) Bottles of wine - *hn3_a15a_ay_wine_pw*

12M - About how many bottles of wine,did you drink on average each week?	No.	Col %	Cum %
1 - None	323	17.1	17.1
2 - Less than 1	320	16.9	34.0
3 - 1	193	10.2	44.2
4 - 2-3	216	11.4	55.6
5 - 4-6	66	3.5	59.1
6 - 7-10	17	0.9	60.0
7 - 11 or more	5	0.3	60.3
.a - Missing	751	39.7	100.0
Total	1891	100.0	

b) Bottles of Spirits - *hn3_a15b_ay_spirits_pw*

12M - About how many bottles of spirits,did you drink on average each week?	No.	Col %	Cum %
1 - None	555	29.3	29.3
2 - Less than 1	236	12.5	41.8
3 - 1	48	2.5	44.4
4 - 2-3	24	1.3	45.6
5 - 4-6	4	0.2	45.8
6 - 7-10	1	0.1	45.9
7 - 11 or more	1	0.1	46.0
.a - Missing	1022	54.0	100.0
Total	1891	100.0	

c) Pints of beer/lager/cider - *hn3_a15c_ay_pints_pw*

12M - About how many pints of beers, did you drink on average each week?	No.	Col %	Cum %
1 - None	254	13.4	13.4
2 - Less than 7	668	35.3	48.8
3 - 7-14	307	16.2	65.0
4 - 15-21	106	5.6	70.6
5 - 22-28	52	2.7	73.3
6 - 28-35	17	0.9	74.2
7 - 36 or more	9	0.5	74.7
.a - Missing	478	25.3	100.0
Total	1891	100.0	

Notes:

A16 What brand of alcohol do you/did you normally drink?*hn3_a16_ay_brand*

Notes: • This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

A17 Are you currently working?*hn3_a17_ay_working*

- Categories
- Quality control
- Used to derive

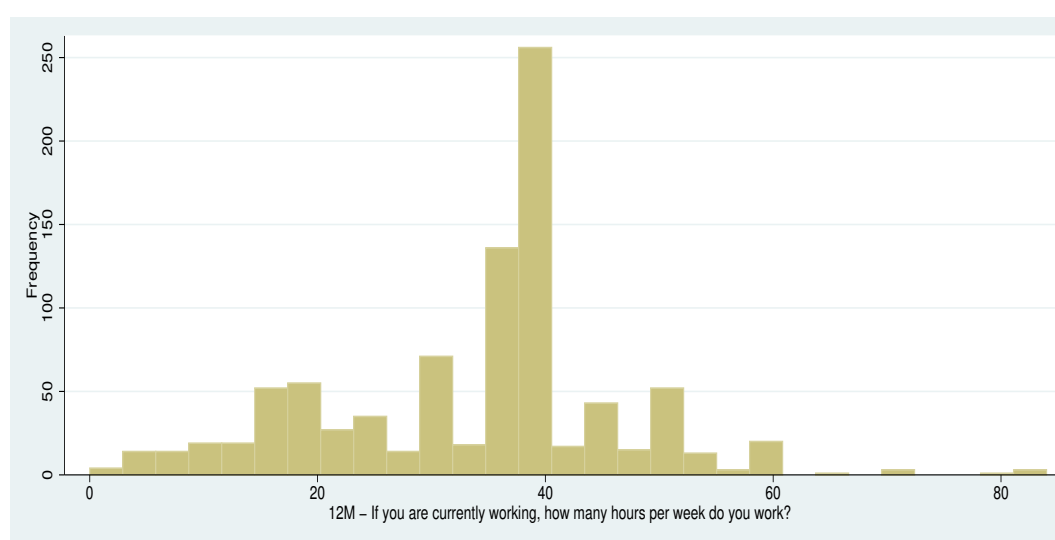
Table 418: 12-months - AY: Are you currently working?

12M - Are you currently working:	No.	Col %	Cum %
1 - Yes	933	33.3	33.3
2 - No	1824	65.0	98.3
.a - Missing	49	1.7	100.0
Total	2806	100.0	

Notes:

A18 If you are currently working, how many hours per week do you work?*hn3_a18_ay_now_work_hours*

- Quality control
- Used to derive
- Descriptives:
 - Total valid responses = 905, number of missing values or data check errors = 1901

Figure 74: 12-months - AY: If you are currently working, how many hours per week do you work?**Notes:**

A21 What is your total household income from all sources before tax and other deductions?*hn3_a21_ay_hhold_income*

- Categories
 - Weekly
 - 1 Less than £77
 - 2 £77-154
 - 3 £155-£230
 - 4 £231-£346
 - 5 £347-£442
 - 6 £443-£558
 - 7 £559-£673
 - 8 £674+
 - Annually
 - 9 Less than £3999
 - 10 £4000-£7999
 - 11 £8000-£11999
 - 12 £12000-£17999
 - 13 £18000-£22999
 - 14 £23000-£28999
 - 15 £29000-£34999
 - 16 £35000+
- Quality control
- Used to derive

– *hn3_dv_a21_ay_hhold_income*

Table 419: 12-months - AY: What is your total household income from all sources before tax and other deductions?

12M - What is your total household income	No.	Col %	Cum %
1 - Less than £77	37	1.3	1.3
2 - £77-154	177	6.3	7.6
3 - £155-£230	144	5.1	12.8
4 - £231-£346	105	3.7	16.5
5 - £347-£442	39	1.4	17.9
6 - £443-£558	27	1.0	18.9
7 - £559-£673	18	0.6	19.5
8 - £674 or more	13	0.5	20.0
9 - Less than £3999	44	1.6	21.5
10 - £4000-£7999	116	4.1	25.7
11 - £8000-£11999	189	6.7	32.4
12 - £12000-£17999	302	10.8	43.2
13 - £18000-£22999	203	7.2	50.4
14 - £23000-£28999	237	8.4	58.8
15 - £29000-34999	178	6.3	65.2
16 - £35000 or more	541	19.3	84.5
.a - Missing	436	15.5	100.0
Total	2806	100.0	

Notes:

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

hn3_a22_ay_hhold_inc_benefit

- Categories
- Quality control
- Used to derive

Table 420: 12-months - AY: What proportion of your household income (including your own) would you say comes from benefits?

12M - What proportion of your household income:	No.	Col %	Cum %
1 - None	1594	56.8	56.8
2 - About a quarter	146	5.2	62.0
3 - About three quarters	75	2.7	64.7
4 - Very little	314	11.2	75.9
5 - About half	106	3.8	79.7
6 - All	392	14.0	93.6
.a - Missing	179	6.4	100.0
Total	2806	100.0	

Notes:

A23 At present do you have any concerns about any of the following aspects of living with or after cancer?**Table 421:** 12-months - AY: At present do you have any concerns about any of the following aspects of living with or after cancer?

- None - *hn3_a23a_ay_lc_none*

12M - Aspects of living with or after cancer: None	No.	Col %	Cum %
1 - Yes	1815	64.7	64.7
2 - No	856	30.5	95.2
.a - Missing	135	4.8	100.0
Total	2806	100.0	

- Financial concerns - *hn3_a23b_ay_lc_financial*

12M - Aspects of living with or after cancer: Financial concerns	No.	Col %	Cum %
1 - Yes	614	21.9	21.9
2 - No	2055	73.2	95.1
.a - Missing	137	4.9	100.0
Total	2806	100.0	

- Staying in college/work - *hn3_a23c_ay_lc_stay_work*

12M - Aspects of living with or after cancer: Staying in work/college	No.	Col %	Cum %
1 - Yes	190	6.8	6.8
2 - No	2479	88.3	95.1
.a - Missing	137	4.9	100.0
Total	2806	100.0	

- Cost of attending appointments - *hn3_a23d_ay_lc_cost*

12M - Aspects of living with or after cancer: Cost of attending appointments	No.	Col %	Cum %
1 - Yes	277	9.9	9.9
2 - No	2390	85.2	95.0
.a - Missing	139	5.0	100.0
Total	2806	100.0	

- Taking time off work/college - *hn3_a23e_ay_lc_time_off*

12M - Aspects of living with or after cancer: Taking time off work/college	No.	Col %	Cum %
1 - Yes	191	6.8	6.8
2 - No	2478	88.3	95.1
.a - Missing	137	4.9	100.0
Total	2806	100.0	

- Returning to work/college - *hn3_a23f_ay_lc_return_work*

12M - Aspects of living with or after cancer: Returning to work/college	No.	Col %	Cum %
1 - Yes	221	7.9	7.9
2 - No	2447	87.2	95.1
.a - Missing	138	4.9	100.0
Total	2806	100.0	

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

hn3_a24_ay_what_you_do

- **Data check**
- **Used to derive**
- **Descriptives:**

Table 422: 12-months - AY: Please tick the box that describes best what you can do:

12M - Please tick the box that describes best what you can do	No.	Col %	Cum %
1 - Able to carry out all normal activities without restriction	969	34.5	34.5
2 - Restricted in physically strenuous activity but able to walk and do light work	728	25.9	60.5
3 - Able to walk and all self care but unable to carry out any work up and about more than 50% of waking hours	267	9.5	70.0
4 - Capable of only limited self care confined to bed or chair more than 50% of waking hours	77	2.7	72.7
	2	0.1	72.8
.a - Missing	763	27.2	100.0
Total	2806	100.0	

Notes:

A25 Please indicate which statements best describes your own health state today**Table 423:** 12-months - AY: Please indicate which statements best describes your own health state todaya) Mobility - *hn3_a25a_ay_hlth_mobility*

12M - Mobility	No.	Col %	Cum %
1 - I have no problems walking about	1282	45.7	45.7
2 - I have slight problems walking about	374	13.3	59.0
3 - I have moderate problems walking about	263	9.4	68.4
4 - I have severe problems walking about	130	4.6	73.0
5 - I am unable to walk about	3	0.1	73.1
.a - Missing	754	26.9	100.0
Total	2806	100.0	

b) Self care - *hn3_a25b_ay_hlth_self_care*

12M - Self care	No.	Col %	Cum %
1 - I have no prob washing or dressing myself	1727	61.5	61.5
2 - I have slight prob washing or dressing myself	185	6.6	68.1
3 - I have moderat prob washing or dressing myself	110	3.9	72.1
4 - I have svr prob washing or dressing myself	26	0.9	73.0
5 - I am unable to wash or dress myself	3	0.1	73.1
.a - Missing	755	26.9	100.0
Total	2806	100.0	

c) Usual activities - *hn3_a25c_ay_hlth_usual_activ*

12M - Usual activities	No.	Col %	Cum %
1 - I have no prob with doing usual activities	1068	38.1	38.1
2 - I have slight probs with doing usual activities	542	19.3	57.4
3 - I have mod probs doing usual activities	300	10.7	68.1
4 - I have sevr probs doing usual activities	114	4.1	72.1
5 - I am unable to do usual actvts	25	0.9	73.0
.a - Missing	757	27.0	100.0
Total	2806	100.0	

d) Pain discomfort - *hn3_a25d_ay_hlth_pain*

12M - Pain discomfort	No.	Col %	Cum %
1 - I have no pain or discomfort	655	23.3	23.3
2 - I have slight pain or discomfort	912	32.5	55.8
3 - I have moderate pain or discomfort	354	12.6	68.5
4 - I have severe pain or discomfort	118	4.2	72.7
5 - I have extreme pain of discomfort	11	0.4	73.1
.a - Missing	756	26.9	100.0
Total	2806	100.0	

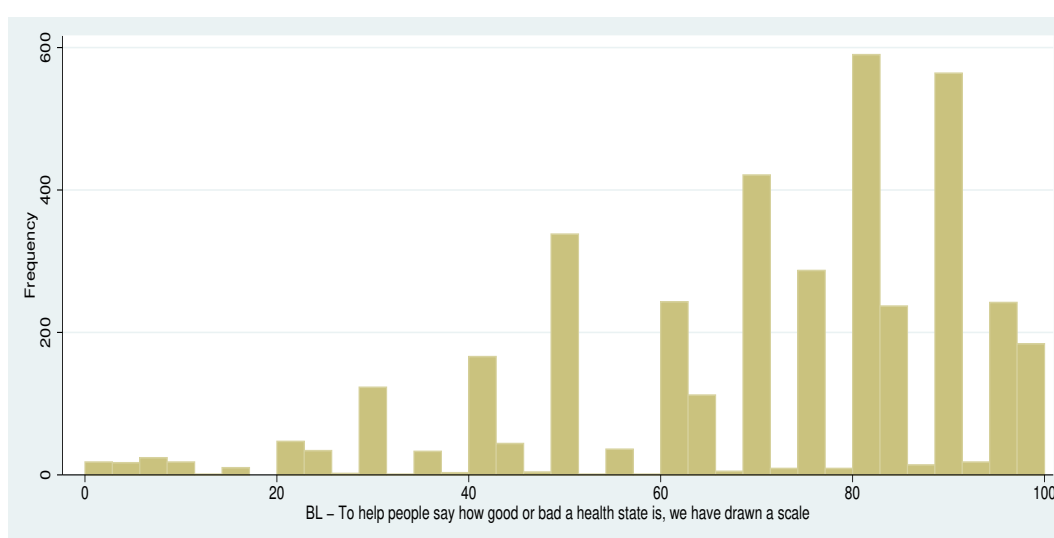
e) Anxiety/depression - *hn1_a25e_ay_hlth_anxiety*

12M - Anxiety/depression	No.	Col %	Cum %
1 - I am not anxious or depressed	1089	38.8	38.8
2 - I am slightly anxious or depressed	623	22.2	61.0
3 - I am moderately anxious or depressed	245	8.7	69.7
4 - I am severely anxious or depressed	62	2.2	72.0
5 - I am extremely anxious or depressed	26	0.9	72.9
.a - Missing	761	27.1	100.0
Total	2806	100.0	

Notes: • Early versions of the 12M - About You questionnaire did not include the EQ5D questionnaire. Response rates for these questions are consequently reduced.

A26 Please describe how good or bad your health state is today*hn3_a26_ay_hlth_state_scale*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 2057, number of missing values or data check errors = 749

Figure 75: 12-months - AY: Please describe how good or bad your health state is today

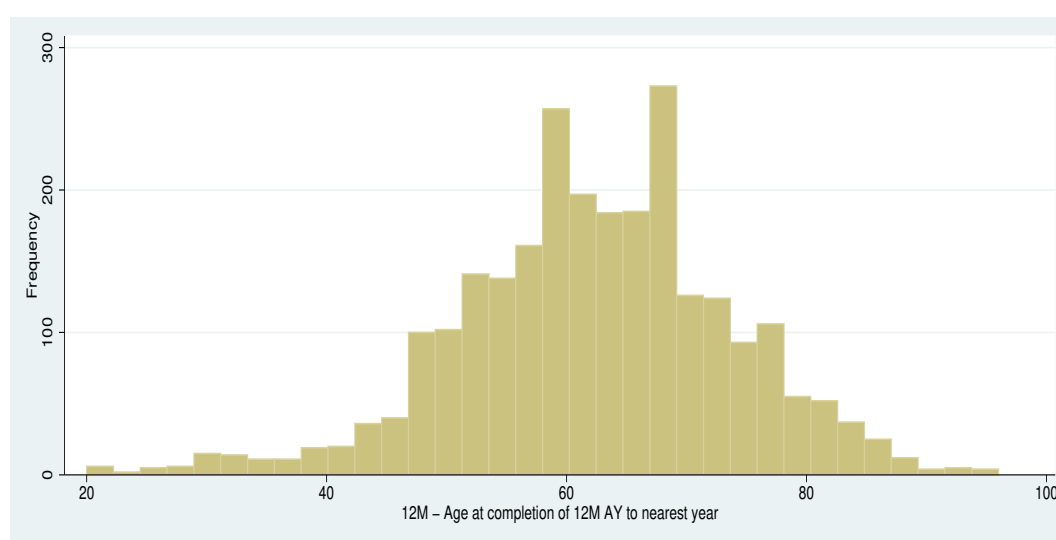
Notes:

- Early versions of the 12M - About You questionnaire did not include the EQ5D questionnaire. Response rates for these questions are consequently reduced.

5.2.2 About You - Derived Variables

A1 comp Age at completion of 12M AY (days)*hn3_dv_ay_age*

- **Data check**
- **Used to derive**
- **Descriptives:**
 - Total valid responses = 2566, number of missing values or data check errors = 240

Figure 76: 12M - AY: Age at completion of 12M AY (days)**Notes:**

A4 comp Composite variable - weight (kg)*hn3_dv_weight_kg*

- **Data check**

- replace hn3_dv_weight_kg=. if hn3_dv_weight_kg<20

- **Used to derive:**

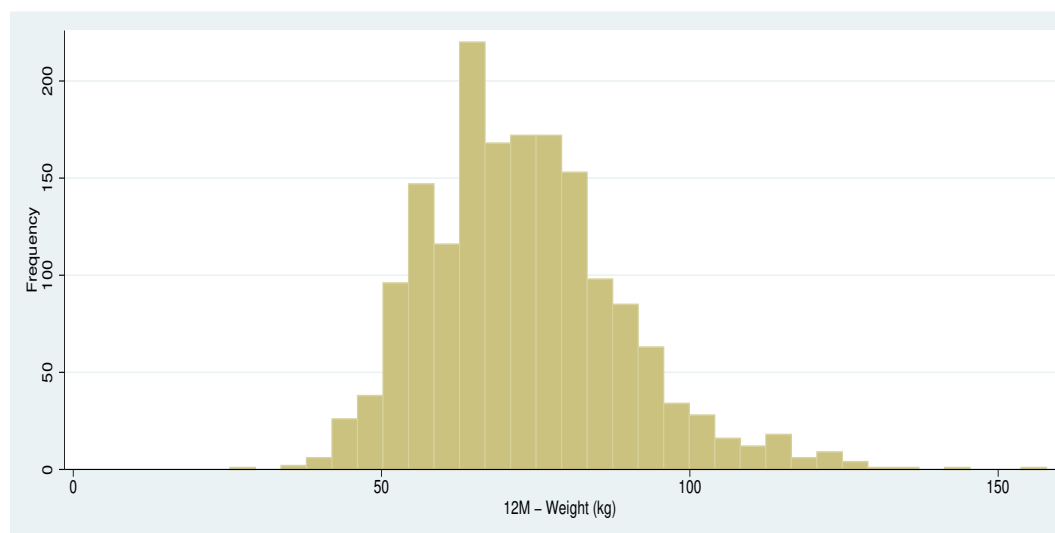
- *hn3_dv_BMI*

- **Stata code to derive variable:**

- gen hn3_dv_weight_kg = .
- replace hn3_dv_weight_kg = hn3_a4_a_ay_kg_weight
- replace hn3_dv_weight_kg = (hn3_a4_b1_ay_stone_weight * 6.35029) if hn3_a4_b1_ay_stone_weight<.
- replace hn3_dv_weight_kg = (hn3_a4_b1_ay_stone_weight * 6.35029) + (hn3_a4_b2_ay_lbs_weight * 0.453592) if hn3_a4_b1_ay_stone_weight<. & hn3_a4_b2_ay_lbs_weight<.

- **Descriptives:**

- Total valid responses = 1694, number of missing values or data check errors = 1112

Figure 77: 12-months - AY: Composite variable - weight (kg)**Notes:**

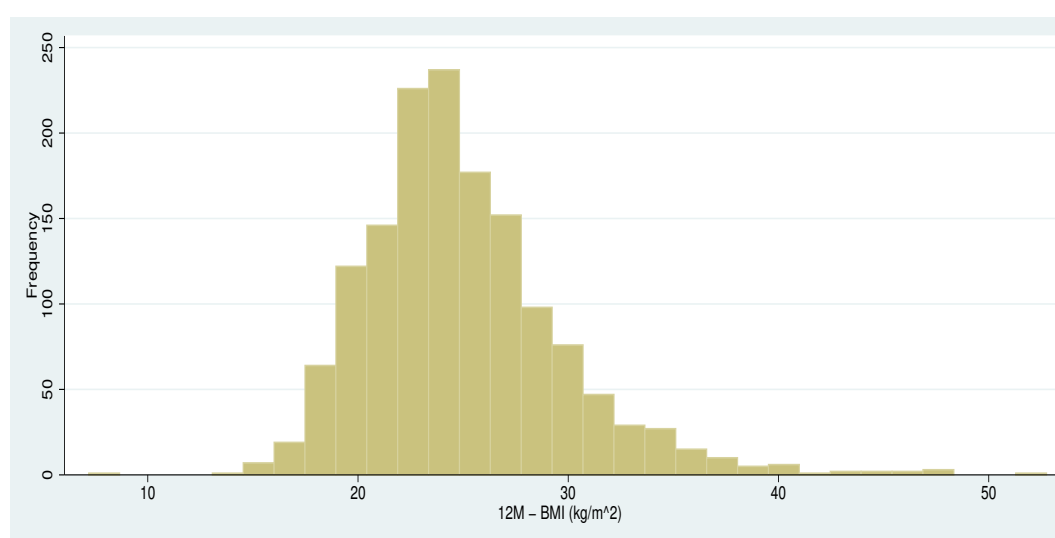
A3-4 comp Composite variable - BMI (kg/m²)*hn3_dv_BMI*

- **Stata code to derive variable:**

- `gen hn3_dv_BMI = hn3_dv_weight_kg/(hn1_dv_height_m^2)`

- **Descriptives:**

- Total valid responses = 1476, number of missing values or data check errors = 1330

Figure 78: 12-months - AY: Composite variable - BMI (kg/m²)**Notes:**

A13-comp1 Are you a current consumer of alcohol?*hn3_dv_drink_ever*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

Table 424: 12-months - AY: Are you a current consumer of alcohol?

12M - Current alcohol consumer	No.	Col %	Cum %
0 - No/never	993	35.4	35.4
1 - Yes	1527	54.4	89.8
.a - Missing	286	10.2	100.0
Total	2806	100.0	

Notes:

A13-comp2 How many days per week do you drink alcohol?*hn3_dv_drink_days*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

Table 425: 12-months - AY: How many days per week do you drink alcohol?

12M - Days per week alcohol consumed	No.	Col %	Cum %
0 - 0	993	35.4	35.4
1 - 1	287	10.2	45.6
2 - 2	298	10.6	56.2
3 - 3	262	9.3	65.6
4 - 4	160	5.7	71.3
5 - 5	181	6.5	77.7
6 - 6	68	2.4	80.1
7 - 7	271	9.7	89.8
.a - Missing	286	10.2	100.0
Total	2806	100.0	

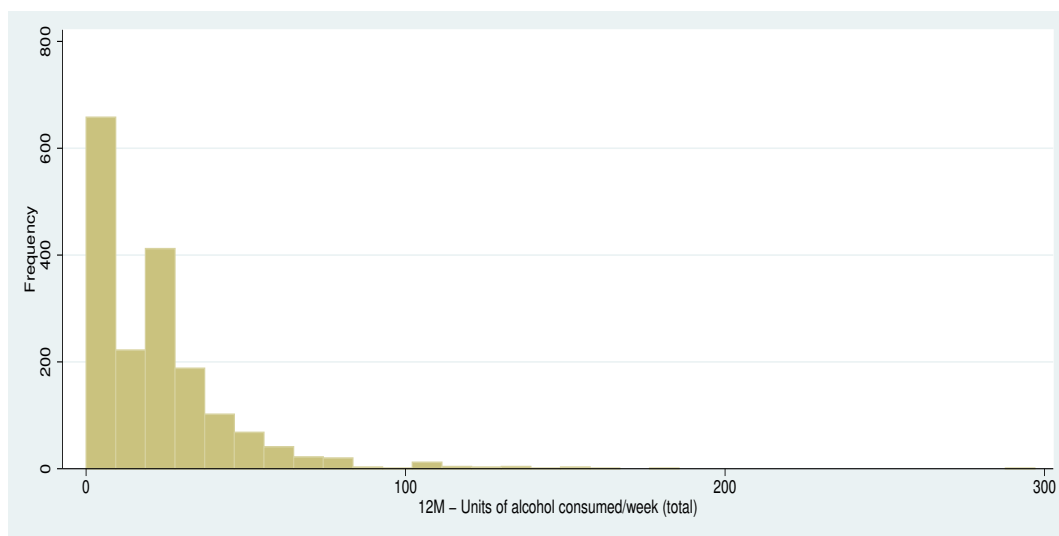
Notes:

A13-comp3 What is your total weekly alcohol consumption (units)?*hn3_dv_total_wk*

- **Stata code to derive variable:**
- **Data check:**
- **Used to derive:**
- **Descriptives:**

– Total valid responses = 1767, number of missing values or data check errors = 1039

Figure 79: What is your total weekly alcohol consumption (units)?



Notes:

5.2.3 Your Outlook

The topics covered in the ‘Your Outlook’ questionnaire are based on the ‘Revised Life Orientation Test (LOT-R)’ (Scheier et al., 1994). Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

B1 In uncertain times, I usually expect the best. - *hn3_b1_yo_uncertain_times*

Table 426: 12-months - LOT-R: In uncertain times, I usually expect the best.

12M - In uncertain times:	No.	Col %	Cum %
1 - Strongly disagree	67	2.4	2.4
2 - Disagree	389	13.9	16.3
3 - Neutral	857	30.5	46.8
4 - Agree	1199	42.7	89.5
5 - Strongly agree	218	7.8	97.3
.a - Missing	76	2.7	100.0
Total	2806	100.0	

B2 It's easy for me to relax. - *hn3_b2_yo_relax*

Table 427: 12-months - LOT-R: It's easy for me to relax.

12M - It is easy for me to relax:	No.	Col %	Cum %
1 - Strongly disagree	87	3.1	3.1
2 - Disagree	600	21.4	24.5
3 - Neutral	555	19.8	44.3
4 - Agree	1202	42.8	87.1
5 - Strongly agree	236	8.4	95.5
.a - Missing	126	4.5	100.0
Total	2806	100.0	

B3 If something can go wrong for me, it will. - *hn3_b3_yo_go_wrong*

Table 428: 12-months - LOT-R: If something can go wrong for me, it will.

12M - If something can go wrong for me:	No.	Col %	Cum %
1 - Strongly disagree	303	10.8	10.8
2 - Disagree	909	32.4	43.2
3 - Neutral	776	27.7	70.8
4 - Agree	604	21.5	92.4
5 - Strongly agree	117	4.2	96.5
.a - Missing	97	3.5	100.0
Total	2806	100.0	

B4 I'm always optimistic about my future - *hn3_b4_yo_optimistic***Table 429:** 12-months - LOT-R: I'm always optimistic about my future

12M - I am always optimistic about my future:	No.	Col %	Cum %
1 - Strongly disagree	70	2.5	2.5
2 - Disagree	370	13.2	15.7
3 - Neutral	700	24.9	40.6
4 - Agree	1307	46.6	87.2
5 - Strongly agree	297	10.6	97.8
.a - Missing	62	2.2	100.0
Total	2806	100.0	

B5 I enjoy my friends a lot. - *hn3_b5_yo_friends***Table 430:** 12-months - LOT-R: I enjoy my friends a lot.

12M - I enjoy my friends a lot:	No.	Col %	Cum %
1 - Strongly disagree	33	1.2	1.2
2 - Disagree	100	3.6	4.7
3 - Neutral	460	16.4	21.1
4 - Agree	1454	51.8	73.0
5 - Strongly agree	704	25.1	98.0
.a - Missing	55	2.0	100.0
Total	2806	100.0	

B6 It's important for me to keep busy - *hn3_b6_yo_keep_busy***Table 431:** 12-months - LOT-R: It's important for me to keep busy

12M - It is important for me to keep busy:	No.	Col %	Cum %
1 - Strongly disagree	30	1.1	1.1
2 - Disagree	170	6.1	7.1
3 - Neutral	526	18.7	25.9
4 - Agree	1414	50.4	76.3
5 - Strongly agree	601	21.4	97.7
.a - Missing	65	2.3	100.0
Total	2806	100.0	

B7 I hardly ever expect things to go my way. - *hn3_b7_yo_go_my_way*

Table 432: 12-months - LOT-R: I hardly ever expect things to go my way.

12M - I hardly ever expect things to go my way:	No.	Col %	Cum %
1 - Strongly disagree	377	13.4	13.4
2 - Disagree	1039	37.0	50.5
3 - Neutral	755	26.9	77.4
4 - Agree	479	17.1	94.4
5 - Strongly agree	97	3.5	97.9
.a - Missing	59	2.1	100.0
Total	2806	100.0	

B8 I don't get upset too easily. - *hn3_b8_yo_upset*

Table 433: 12-months - LOT-R: I don't get upset too easily.

12M - I do not get upset too easily:	No.	Col %	Cum %
1 - Strongly disagree	108	3.8	3.8
2 - Disagree	513	18.3	22.1
3 - Neutral	644	23.0	45.1
4 - Agree	1251	44.6	89.7
5 - Strongly agree	235	8.4	98.0
.a - Missing	55	2.0	100.0
Total	2806	100.0	

B9 I rarely count on good things happening to me. - *hn3_b9_yo_good_things*

Table 434: 12-months - LOT-R: I rarely count on good things happening to me.

12M - I rarely count on good things happening to me:	No.	Col %	Cum %
1 - Strongly disagree	323	11.5	11.5
2 - Disagree	886	31.6	43.1
3 - Neutral	832	29.7	72.7
4 - Agree	614	21.9	94.6
5 - Strongly agree	101	3.6	98.2
.a - Missing	50	1.8	100.0
Total	2806	100.0	

B10 Overall, I expect more good things to happen to me than bad. - *hn3_b10_yo_overall*

Table 435: 12-months - LOT-R: Overall, I expect more good things to happen to me than bad.

12M - Overall, I expect more good things to happen to me than bad.:	No.	Col %	Cum %
1 - Strongly disagree	77	2.7	2.7
2 - Disagree	317	11.3	14.0
3 - Neutral	781	27.8	41.9
4 - Agree	1284	45.8	87.6
5 - Strongly agree	308	11.0	98.6
.a - Missing	39	1.4	100.0
Total	2806	100.0	

Notes:

5.2.4 Your General Health - EORTC QLQ-C30

The topics covered in the ‘Your General Health’ questionnaire are based on the ‘EORTC QLQ-C30’ questionnaire (Aaronson et al., 1993). Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

C1 Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? - *hn3_c1_ygh_stren_acttrouble*

Table 436: 12-months - QLQ-C30: Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?

12M - Do you have any trouble doing strenuous activities,like carrying a heavy s	No.	Col %	Cum %
1 - Not at all	959	34.2	34.2
2 - A little	973	34.7	68.9
3 - Quite a bit	471	16.8	85.6
4 - Very much	378	13.5	99.1
.a - Missing	25	0.9	100.0
Total	2806	100.0	

C2 Do you have any trouble taking a long walk? - *hn3_c2_ygh_long_walktrouble*

Table 437: 12-months - QLQ-C30: Do you have any trouble taking a long walk?

12M - Do you have any trouble taking a long walk?	No.	Col %	Cum %
1 - Not at all	1124	40.1	40.1
2 - A little	778	27.7	67.8
3 - Quite a bit	382	13.6	81.4
4 - Very much	494	17.6	99.0
.a - Missing	28	1.0	100.0
Total	2806	100.0	

C3 Do you have any trouble taking a short walk outside of the house? - *hn3_c3_ygh_short_walktrouble*

Table 438: 12-months - QLQ-C30: Do you have any trouble taking a short walk outside of the house?

12M - Do you have any trouble taking a short walk outside of the house?	No.	Col %	Cum %
1 - Not at all	2067	73.7	73.7
2 - A little	426	15.2	88.8
3 - Quite a bit	198	7.1	95.9
4 - Very much	89	3.2	99.1
.a - Missing	26	0.9	100.0
Total	2806	100.0	

C4 Do you need to stay in bed or a chair during the day? - *hn3_c4_ygh_stay_bed_daytime***Table 439:** 12-months - QLQ-C30: Do you need to stay in bed or a chair during the day?

12M - Do you need to stay in bed or a chair during the day?	No.	Col %	Cum %
1 - Not at all	1890	67.4	67.4
2 - A little	568	20.2	87.6
3 - Quite a bit	231	8.2	95.8
4 - Very much	68	2.4	98.3
.a - Missing	49	1.7	100.0
Total	2806	100.0	

C5 Do you need help with eating, dressing, washing yourself or using the toilet? - *hn3_c5_ygh_help_with_eating***Table 440:** 12-months - QLQ-C30: Do you need help with eating, dressing, washing yourself or using the toilet?

12M - Do you need help with eating, dressing, washing yourself or using the toilet	No.	Col %	Cum %
1 - Not at all	2481	88.4	88.4
2 - A little	210	7.5	95.9
3 - Quite a bit	58	2.1	98.0
4 - Very much	22	0.8	98.8
.a - Missing	35	1.2	100.0
Total	2806	100.0	

C6 Were you limited in doing either your work or other daily activities? - *hn3_c6_ygh_limit_daily_activ***Table 441:** 12-months - QLQ-C30: Were you limited in doing either your work or other daily activities?

12M - Were you limited in doing either your work or other daily activities?	No.	Col %	Cum %
1 - Not at all	1555	55.4	55.4
2 - A little	780	27.8	83.2
3 - Quite a bit	289	10.3	93.5
4 - Very much	141	5.0	98.5
.a - Missing	41	1.5	100.0
Total	2806	100.0	

C7 Were you limited in pursuing your hobbies or other leisure time activities? - *hn3_c7_ygh_limit_hobbies*

Table 442: 12-months - QLQ-C30: Were you limited in pursuing your hobbies or other leisure time activities?

12M - Were you limited in pursuing your hobbies or other leisure time activities	No.	Col %	Cum %
1 - Not at all	1506	53.7	53.7
2 - A little	726	25.9	79.5
3 - Quite a bit	315	11.2	90.8
4 - Very much	212	7.6	98.3
.a - Missing	47	1.7	100.0
Total	2806	100.0	

C8 Were you short of breath? - *hn3_c8_ygh_short_of_breath*

Table 443: 12-months - QLQ-C30: Were you short of breath?

12M - Were you short of breath?	No.	Col %	Cum %
1 - Not at all	1760	62.7	62.7
2 - A little	686	24.4	87.2
3 - Quite a bit	221	7.9	95.0
4 - Very much	109	3.9	98.9
.a - Missing	30	1.1	100.0
Total	2806	100.0	

C9 Have you had pain? - *hn3_c9_ygh_had_pain*

Table 444: 12-months - QLQ-C30: Have you had pain?

12M - Have you had pain?	No.	Col %	Cum %
1 - Not at all	1222	43.5	43.5
2 - A little	1045	37.2	80.8
3 - Quite a bit	345	12.3	93.1
4 - Very much	166	5.9	99.0
.a - Missing	28	1.0	100.0
Total	2806	100.0	

C10 Did you need to rest? - *hn3_c10_ygh_need_to_rest***Table 445:** 12-months - QLQ-C30: Did you need to rest?

12M - Did you need to rest?	No.	Col %	Cum %
1 - Not at all	860	30.6	30.6
2 - A little	1284	45.8	76.4
3 - Quite a bit	433	15.4	91.8
4 - Very much	198	7.1	98.9
.a - Missing	31	1.1	100.0
Total	2806	100.0	

C11 Have you had trouble sleeping? - *hn3_c11_ygh_sleep_trouble***Table 446:** 12-months - QLQ-C30: Have you had trouble sleeping?

12M - Have you had trouble sleeping?	No.	Col %	Cum %
1 - Not at all	1114	39.7	39.7
2 - A little	993	35.4	75.1
3 - Quite a bit	419	14.9	90.0
4 - Very much	257	9.2	99.2
.a - Missing	23	0.8	100.0
Total	2806	100.0	

C12 Have you felt weak? - *hn3_c12_ygh_felt_weak***Table 447:** 12-months - QLQ-C30: Have you felt weak?

12M - Have you felt weak?	No.	Col %	Cum %
1 - Not at all	1120	39.9	39.9
2 - A little	1066	38.0	77.9
3 - Quite a bit	376	13.4	91.3
4 - Very much	217	7.7	99.0
.a - Missing	27	1.0	100.0
Total	2806	100.0	

C13 Have you lacked appetite? - *hn3_c13_ygh_lacked_appetite***Table 448:** 12-months - QLQ-C30: Have you lacked appetite?

12M - Have you lacked appetite?	No.	Col %	Cum %
1 - Not at all	1545	55.1	55.1
2 - A little	665	23.7	78.8
3 - Quite a bit	321	11.4	90.2
4 - Very much	239	8.5	98.7
.a - Missing	36	1.3	100.0
Total	2806	100.0	

C14 Have you felt nauseated? - *hn3_c14_ygh_felt_auseated***Table 449:** 12-months - QLQ-C30: Have you felt nauseated?

12M - Have you felt nauseated?	No.	Col %	Cum %
1 - Not at all	2155	76.8	76.8
2 - A little	479	17.1	93.9
3 - Quite a bit	99	3.5	97.4
4 - Very much	40	1.4	98.8
.a - Missing	33	1.2	100.0
Total	2806	100.0	

C15 Have you vomited? - *hn3_c15_ygh_vomited***Table 450:** 12-months - QLQ-C30: Have you vomited?

12M - Have you vomited?	No.	Col %	Cum %
1 - Not at all	2549	90.8	90.8
2 - A little	172	6.1	97.0
3 - Quite a bit	39	1.4	98.4
4 - Very much	23	0.8	99.2
.a - Missing	23	0.8	100.0
Total	2806	100.0	

C16 Have you been constipated? - *hn3_c16_ygh_constipated***Table 451:** 12-months - QLQ-C30: Have you been constipated?

12M - Have you been constipated?	No.	Col %	Cum %
1 - Not at all	1878	66.9	66.9
2 - A little	621	22.1	89.1
3 - Quite a bit	191	6.8	95.9
4 - Very much	91	3.2	99.1
.a - Missing	25	0.9	100.0
Total	2806	100.0	

C17 Have you had diarrhoea? - *hn3_c17_ygh_diarrhoea***Table 452:** 12-months - QLQ-C30: Have you had diarrhoea?

12M - Have you had diarrhoea?	No.	Col %	Cum %
1 - Not at all	2368	84.4	84.4
2 - A little	320	11.4	95.8
3 - Quite a bit	65	2.3	98.1
4 - Very much	29	1.0	99.1
.a - Missing	24	0.9	100.0
Total	2806	100.0	

C18 Were you tired? - *hn3_c18_ygh_tired***Table 453:** 12-months - QLQ-C30: Were you tired?

12M - Were you tired?	No.	Col %	Cum %
1 - Not at all	529	18.9	18.9
2 - A little	1455	51.9	70.7
3 - Quite a bit	540	19.2	90.0
4 - Very much	260	9.3	99.2
.a - Missing	22	0.8	100.0
Total	2806	100.0	

C19 Did pain interfere with your daily activities? - *hn3_c19_ygh_pain_daily_activ*

Table 454: 12-months - QLQ-C30: Did pain interfere with your daily activities?

12M - Did pain interfere with your daily activities?	No.	Col %	Cum %
1 - Not at all	1734	61.8	61.8
2 - A little	709	25.3	87.1
3 - Quite a bit	210	7.5	94.5
4 - Very much	127	4.5	99.1
.a - Missing	26	0.9	100.0
Total	2806	100.0	

C20 Have you had difficulty in concentrating on things, like reading a newspaper or watching television? - *hn3_c20_ygh_difficulty_conc*

Table 455: 12-months - QLQ-C30: Have you had difficulty in concentrating on things, like reading a newspaper or watching television?

12M - Have you had difficulty in concentrating on things, like reading a newspaper	No.	Col %	Cum %
1 - Not at all	1808	64.4	64.4
2 - A little	667	23.8	88.2
3 - Quite a bit	211	7.5	95.7
4 - Very much	96	3.4	99.1
.a - Missing	24	0.9	100.0
Total	2806	100.0	

C21 Did you feel tense? - *hn3_c21_ygh_feel_tense*

Table 456: 12-months - QLQ-C30: Did you feel tense?

12M - Did you feel tense?	No.	Col %	Cum %
1 - Not at all	1371	48.9	48.9
2 - A little	1041	37.1	86.0
3 - Quite a bit	275	9.8	95.8
4 - Very much	94	3.3	99.1
.a - Missing	25	0.9	100.0
Total	2806	100.0	

C22 Did you worry? - *hn3_c22_ygh_worry***Table 457:** 12-months - QLQ-C30: Did you worry?

12M - Did you worry?	No.	Col %	Cum %
1 - Not at all	1041	37.1	37.1
2 - A little	1225	43.7	80.8
3 - Quite a bit	372	13.3	94.0
4 - Very much	142	5.1	99.1
.a - Missing	26	0.9	100.0
Total	2806	100.0	

C23 Did you feel irritable? - *hn3_c23_ygh_irritable***Table 458:** 12-months - QLQ-C30: Did you feel irritable?

12M - Did you feel irritable?	No.	Col %	Cum %
1 - Not at all	1285	45.8	45.8
2 - A little	1088	38.8	84.6
3 - Quite a bit	299	10.7	95.2
4 - Very much	106	3.8	99.0
.a - Missing	28	1.0	100.0
Total	2806	100.0	

C24 Did you feel depressed? - *hn3_c24_ygh_depressed***Table 459:** 12-months - QLQ-C30: Did you feel depressed?

12M - Did you feel depressed?	No.	Col %	Cum %
1 - Not at all	1632	58.2	58.2
2 - A little	770	27.4	85.6
3 - Quite a bit	240	8.6	94.2
4 - Very much	133	4.7	98.9
.a - Missing	31	1.1	100.0
Total	2806	100.0	

C25 Have you had difficulty remembering things? - *hn3_c25_ygh_mem_diff*

Table 460: 12-months - QLQ-C30: Have you had difficulty remembering things?

12M - Have you had difficulty remembering things?	No.	Col %	Cum %
1 - Not at all	1183	42.2	42.2
2 - A little	1222	43.5	85.7
3 - Quite a bit	260	9.3	95.0
4 - Very much	118	4.2	99.2
.a - Missing	23	0.8	100.0
Total	2806	100.0	

C26 Has your physical condition or medical treatment interfered with your family life? - *hn3_c26_ygh_family_life*

Table 461: 12-months - QLQ-C30: Has your physical condition or medical treatment interfered with your family life?

12M - Has your physical condition or medical treatment interfered with your fami	No.	Col %	Cum %
1 - Not at all	1533	54.6	54.6
2 - A little	812	28.9	83.6
3 - Quite a bit	279	9.9	93.5
4 - Very much	147	5.2	98.8
.a - Missing	35	1.2	100.0
Total	2806	100.0	

C27 Has your physical condition or medical treatment interfered with your social activities? - *hn3_c27_ygh_social_activ*

Table 462: 12-months - QLQ-C30: Has your physical condition or medical treatment interfered with your social activities?

12M - Has your physical condition or medical treatment interfered with your soci	No.	Col %	Cum %
1 - Not at all	1289	45.9	45.9
2 - A little	865	30.8	76.8
3 - Quite a bit	383	13.6	90.4
4 - Very much	240	8.6	99.0
.a - Missing	29	1.0	100.0
Total	2806	100.0	

C28 Has your physical condition or medical treatment interfered caused you financial difficulties?

- *hn3_c28_ygh_financial_diff*

Table 463: 12-months - QLQ-C30: Has your physical condition or medical treatment interfered caused you financial difficulties?

12M - Has your physical condition or medical treatment caused you financial diff	No.	Col %	Cum %
1 - Not at all	1786	63.6	63.6
2 - A little	573	20.4	84.1
3 - Quite a bit	241	8.6	92.7
4 - Very much	176	6.3	98.9
.a - Missing	30	1.1	100.0
Total	2806	100.0	

C29 How would you rate your overall health during the past week? - *hn3_c29_ygh_health_past_wk*

Table 464: 12-months - QLQ-C30: How would you rate your overall health during the past week?

12M - How would you rate your overall health during the past week?(on a scale of	No.	Col %	Cum %
1 - Very poor	53	1.9	1.9
2 - 2	80	2.9	4.7
3 - 3	229	8.2	12.9
4 - 4	446	15.9	28.8
5 - 5	727	25.9	54.7
6 - 6	944	33.6	88.3
7 - Excellent	303	10.8	99.1
.a - Missing	24	0.9	100.0
Total	2806	100.0	

C30 How would you rate your overall quality of life during the past week? - *hn3_c30_ygh_lifequal_past_wk*

Table 465: 12-months - QLQ-C30: How would you rate your overall quality of life during the past week?

12M - How would you rate your overall quality of life during the past week?	No.	Col %	Cum %
1 - Very poor	55	2.0	2.0
2 - 2	99	3.5	5.5
3 - 3	222	7.9	13.4
4 - 4	380	13.5	26.9
5 - 5	604	21.5	48.5
6 - 6	954	34.0	82.5
7 - Excellent	471	16.8	99.3
.a - Missing	21	0.7	100.0
Total	2806	100.0	

Notes:

5.2.5 Specific Aspects of Your health

The topics covered in the ‘Specific Aspects of Your health’ questionnaire are based on the ‘EORTC QLQ-H&N35’ questionnaire (Bjordal et al., 1993). Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

D1 Have you had pain in the mouth? - *hn3_d1_sayh_pain_mouth*

Table 466: 12-months - HN35: Have you had pain in the mouth?

12M - Have you had pain in your mouth:	No.	Col %	Cum %
1 - Not at all	1630	58.1	58.1
2 - A little	818	29.2	87.2
3 - Quite a bit	231	8.2	95.5
4 - Very much	91	3.2	98.7
.a - Missing	36	1.3	100.0
Total	2806	100.0	

D2 Have you had pain in the jaw? - *hn3_d2_sayh_pain_jaw*

Table 467: 12-months - HN35: Have you had pain in the jaw?

12M - Have you had pain in your jaw:	No.	Col %	Cum %
1 - Not at all	1801	64.2	64.2
2 - A little	700	24.9	89.1
3 - Quite a bit	185	6.6	95.7
4 - Very much	66	2.4	98.1
.a - Missing	54	1.9	100.0
Total	2806	100.0	

D3 Have you had soreness in the mouth? - *hn3_d3_sayh_soreness_mouth*

Table 468: 12-months - HN35: Have you had soreness in the mouth?

12M - Have you had soreness in your mouth:	No.	Col %	Cum %
1 - Not at all	1453	51.8	51.8
2 - A little	945	33.7	85.5
3 - Quite a bit	260	9.3	94.7
4 - Very much	108	3.8	98.6
.a - Missing	40	1.4	100.0
Total	2806	100.0	

D4 Have you had a painful throat? - *hn3_d4_sayh_painful_throat***Table 469:** 12-months - HN35: Have you had a painful throat?

12M - Have you had problems swallowing liquid:	No.	Col %	Cum %
1 - Not at all	1631	58.1	58.1
2 - A little	816	29.1	87.2
3 - Quite a bit	228	8.1	95.3
4 - Very much	83	3.0	98.3
.a - Missing	48	1.7	100.0
Total	2806	100.0	

D5 Have you had problems swallowing liquid? - *hn3_d5_sayh_swallow_liquid***Table 470:** 12-months - HN35: Have you had problems swallowing liquid?

12M - Have you had problems swallowing liquid:	No.	Col %	Cum %
1 - Not at all	2093	74.6	74.6
2 - A little	490	17.5	92.1
3 - Quite a bit	105	3.7	95.8
4 - Very much	88	3.1	98.9
.a - Missing	30	1.1	100.0
Total	2806	100.0	

D6 Have you had problems swallowing pureed food? - *hn3_d6_sayh_swallow_pureed***Table 471:** 12-months - HN35: Have you had problems swallowing pureed food?

12M - Have you had problems swallowing pureed food:	No.	Col %	Cum %
1 - Not at all	2193	78.2	78.2
2 - A little	360	12.8	91.0
3 - Quite a bit	109	3.9	94.9
4 - Very much	90	3.2	98.1
.a - Missing	54	1.9	100.0
Total	2806	100.0	

D7 Have you had problems swallowing solid food? - *hn3_d7_sayh_swallow_solid***Table 472:** 12-months - HN35: Have you had problems swallowing solid food?

12M - Have you had problems swallowing solid food:	No.	Col %	Cum %
1 - Not at all	1229	43.8	43.8
2 - A little	858	30.6	74.4
3 - Quite a bit	331	11.8	86.2
4 - Very much	347	12.4	98.5
.a - Missing	41	1.5	100.0
Total	2806	100.0	

D8 Have you choked when swallowing? - *hn3_d8_sayh_choked***Table 473:** 12-months - HN35: Have you choked when swallowing?

12M - Have you choked when swallowing:	No.	Col %	Cum %
1 - Not at all	1911	68.1	68.1
2 - A little	624	22.2	90.3
3 - Quite a bit	144	5.1	95.5
4 - Very much	84	3.0	98.5
.a - Missing	43	1.5	100.0
Total	2806	100.0	

D9 Have you had problems with teeth? - *hn3_d9_sayh_problems_teeth***Table 474:** 12-months - HN35: Have you had problems with teeth?

12M - Have you had problems with your teeth:	No.	Col %	Cum %
1 - Not at all	1686	60.1	60.1
2 - A little	644	23.0	83.0
3 - Quite a bit	194	6.9	90.0
4 - Very much	205	7.3	97.3
.a - Missing	77	2.7	100.0
Total	2806	100.0	

D10 Have you had problems opening mouth? - *hn3_d10_sayh_open_mouth*

Table 475: 12-months - HN35: Have you had problems opening mouth?

12M - Have you had problems opening your mouth wide:	No.	Col %	Cum %
1 - Not at all	1741	62.0	62.0
2 - A little	659	23.5	85.5
3 - Quite a bit	194	6.9	92.4
4 - Very much	182	6.5	98.9
.a - Missing	30	1.1	100.0
Total	2806	100.0	

D11 Have you had a dry mouth? - *hn3_d11_sayh_dry_mouth*

Table 476: 12-months - HN35: Have you had a dry mouth?

12M - Have you had a dry mouth:	No.	Col %	Cum %
1 - Not at all	634	22.6	22.6
2 - A little	809	28.8	51.4
3 - Quite a bit	658	23.4	74.9
4 - Very much	677	24.1	99.0
.a - Missing	28	1.0	100.0
Total	2806	100.0	

D12 Have you had sticky saliva? - *hn3_d12_sayh_sticky_saliva*

Table 477: 12-months - HN35: Have you had sticky saliva?

12M - Have you had sticky saliva:	No.	Col %	Cum %
1 - Not at all	1092	38.9	38.9
2 - A little	741	26.4	65.3
3 - Quite a bit	501	17.9	83.2
4 - Very much	429	15.3	98.5
.a - Missing	43	1.5	100.0
Total	2806	100.0	

D13 Have you had problems with your sense of smell? - *hn3_d13_sayh_sense_smell***Table 478:** 12-months - HN35: Have you had problems with your sense of smell?

12M - Have you had problems with your sense of smell:	No.	Col %	Cum %
1 - Not at all	1928	68.7	68.7
2 - A little	505	18.0	86.7
3 - Quite a bit	157	5.6	92.3
4 - Very much	187	6.7	99.0
.a - Missing	29	1.0	100.0
Total	2806	100.0	

D14 Have you had problems with your sense of taste? - *hn3_d14_sayh_sense_taste***Table 479:** 12-months - HN35: Have you had problems with your sense of taste?

12M - Have you had problems with your sense of taste:	No.	Col %	Cum %
1 - Not at all	1126	40.1	40.1
2 - A little	805	28.7	68.8
3 - Quite a bit	443	15.8	84.6
4 - Very much	401	14.3	98.9
.a - Missing	31	1.1	100.0
Total	2806	100.0	

D15 Have you coughed? - *hn3_d15_sayh_coughed***Table 480:** 12-months - HN35: Have you coughed?

12M - Have you coughed:	No.	Col %	Cum %
1 - Not at all	944	33.6	33.6
2 - A little	1302	46.4	80.0
3 - Quite a bit	405	14.4	94.5
4 - Very much	120	4.3	98.8
.a - Missing	35	1.2	100.0
Total	2806	100.0	

D16 Have you been hoarse? - *hn3_d16_sayh_hoarse*

Table 481: 12-months - HN35: Have you been hoarse?

12M - Have you been hoarse:	No.	Col %	Cum %
1 - Not at all	1441	51.4	51.4
2 - A little	880	31.4	82.7
3 - Quite a bit	292	10.4	93.1
4 - Very much	132	4.7	97.8
.a - Missing	61	2.2	100.0
Total	2806	100.0	

D17 Have you felt ill? - *hn3_d17_sayh_felt_ill*

Table 482: 12-months - HN35: Have you felt ill?

12M - Have you felt ill:	No.	Col %	Cum %
1 - Not at all	1807	64.4	64.4
2 - A little	739	26.3	90.7
3 - Quite a bit	154	5.5	96.2
4 - Very much	67	2.4	98.6
.a - Missing	39	1.4	100.0
Total	2806	100.0	

D18 Has your appearance bothered you? - *hn3_d18_sayh_appearance*

Table 483: 12-months - HN35: Has your appearance bothered you?

12M - Has your appearance bothered you:	No.	Col %	Cum %
1 - Not at all	1803	64.3	64.3
2 - A little	651	23.2	87.5
3 - Quite a bit	195	6.9	94.4
4 - Very much	126	4.5	98.9
.a - Missing	31	1.1	100.0
Total	2806	100.0	

D19 Have you had trouble eating? - *hn3_d19_sayh_trouble_eating*

Table 484: 12-months - HN35: Have you had trouble eating?

12M - Have you had trouble eating:	No.	Col %	Cum %
1 - Not at all	1304	46.5	46.5
2 - A little	848	30.2	76.7
3 - Quite a bit	310	11.0	87.7
4 - Very much	308	11.0	98.7
.a - Missing	36	1.3	100.0
Total	2806	100.0	

D20 Have you had trouble eating in front of family? - *hn3_d20_sayh_front_family*

Table 485: 12-months - HN35: Have you had trouble eating in front of family?

12M - Have you had trouble eating in front of family:	No.	Col %	Cum %
1 - Not at all	2036	72.6	72.6
2 - A little	384	13.7	86.2
3 - Quite a bit	146	5.2	91.4
4 - Very much	175	6.2	97.7
.a - Missing	65	2.3	100.0
Total	2806	100.0	

D21 Have you had trouble eating in front of others? - *hn3_d21_sayh_front_others*

Table 486: 12-months - HN35: Have you had trouble eating in front of others?

12M - Have you had trouble eating in front of others:	No.	Col %	Cum %
1 - Not at all	1770	63.1	63.1
2 - A little	478	17.0	80.1
3 - Quite a bit	214	7.6	87.7
4 - Very much	285	10.2	97.9
.a - Missing	59	2.1	100.0
Total	2806	100.0	

D22 Have you had trouble enjoying meals? - *hn3_d22_sayh_enjoying*

Table 487: 12-months - HN35: Have you had trouble enjoying meals?

12M - Have you had trouble enjoying meals:	No.	Col %	Cum %
1 - Not at all	1207	43.0	43.0
2 - A little	747	26.6	69.6
3 - Quite a bit	387	13.8	83.4
4 - Very much	411	14.6	98.1
.a - Missing	54	1.9	100.0
Total	2806	100.0	

D23 Have you had trouble talking to other people? - *hn3_d23_sayh_talking_people*

Table 488: 12-months - HN35: Have you had trouble talking to other people?

12M - Have you had trouble talking to other people:	No.	Col %	Cum %
1 - Not at all	1784	63.6	63.6
2 - A little	649	23.1	86.7
3 - Quite a bit	198	7.1	93.8
4 - Very much	144	5.1	98.9
.a - Missing	31	1.1	100.0
Total	2806	100.0	

D24 Have you had trouble talking on the telephone? - *hn3_d24_sayh_talking_phone*

Table 489: 12-months - HN35: Have you had trouble talking on the telephone?

12M - Have you had trouble talking on the telephone:	No.	Col %	Cum %
1 - Not at all	1695	60.4	60.4
2 - A little	644	23.0	83.4
3 - Quite a bit	216	7.7	91.1
4 - Very much	217	7.7	98.8
.a - Missing	34	1.2	100.0
Total	2806	100.0	

D25 Have you had trouble having social contact with family? - *hn3_d25_sayh_social_family***Table 490:** 12-months - HN35: Have you had trouble having social contact with family?

12M - Have you had trouble having social contact with family:	No.	Col %	Cum %
1 - Not at all	2283	81.4	81.4
2 - A little	305	10.9	92.2
3 - Quite a bit	109	3.9	96.1
4 - Very much	70	2.5	98.6
.a - Missing	39	1.4	100.0
Total	2806	100.0	

D26 Have you had trouble having social contact with friends? - *hn3_d26_sayh_social_friends***Table 491:** 12-months - HN35: Have you had trouble having social contact with friends?

12M - Have you had trouble having social contact with friends:	No.	Col %	Cum %
1 - Not at all	2044	72.8	72.8
2 - A little	437	15.6	88.4
3 - Quite a bit	170	6.1	94.5
4 - Very much	117	4.2	98.6
.a - Missing	38	1.4	100.0
Total	2806	100.0	

D27 Have you had trouble going out in public? - *hn3_d27_sayh_out_public***Table 492:** 12-months - HN35: Have you had trouble going out in public?

12M - Have you had trouble going out in public:	No.	Col %	Cum %
1 - Not at all	2205	78.6	78.6
2 - A little	339	12.1	90.7
3 - Quite a bit	139	5.0	95.6
4 - Very much	92	3.3	98.9
.a - Missing	31	1.1	100.0
Total	2806	100.0	

D28 Have you had trouble having physical contact with family or friends? - *hn3_d28_sayh_physical*

Table 493: 12-months - HN35: Have you had trouble having physical contact with family or friends?

12M - Have you had trouble having physical contact with family or friends:	No.	Col %	Cum %
1 - Not at all	2226	79.3	79.3
2 - A little	335	11.9	91.3
3 - Quite a bit	117	4.2	95.4
4 - Very much	73	2.6	98.0
.a - Missing	55	2.0	100.0
Total	2806	100.0	

D29 Have you felt less interest in sex? - *hn3_d29_sayh_sex*

Table 494: 12-months - HN35: Have you felt less interest in sex?

12M - Have you felt less interest in sex:	No.	Col %	Cum %
1 - Not at all	1000	35.6	35.6
2 - A little	552	19.7	55.3
3 - Quite a bit	442	15.8	71.1
4 - Very much	517	18.4	89.5
.a - Missing	295	10.5	100.0
Total	2806	100.0	

D30 Have you felt less sexual enjoyment? - *hn3_d30_sayh_sex_enjoy*

Table 495: 12-months - HN35: Have you felt less sexual enjoyment?

12M - Have you felt less sexual enjoyment:	No.	Col %	Cum %
1 - Not at all	1032	36.8	36.8
2 - A little	491	17.5	54.3
3 - Quite a bit	374	13.3	67.6
4 - Very much	542	19.3	86.9
.a - Missing	367	13.1	100.0
Total	2806	100.0	

D31 Have you used painkillers? - *hn3_d31_sayh_painkillers***Table 496:** 12-months - HN35: Have you used painkillers?

12M - Have you used painkillers:	No.	Col %	Cum %
1 - Yes	1212	43.2	43.2
2 - No	1560	55.6	98.8
.a - Missing	34	1.2	100.0
Total	2806	100.0	

D32 Have you taken any nutritional supplements (excluding vitamins)? - *hn3_d32_sayh_nutritional***Table 497:** 12-months - HN35: Have you taken any nutritional supplements (excluding vitamins)?

12M - Have you taken any nutritional supplements (excluding vitamins):	No.	Col %	Cum %
1 - Yes	841	30.0	30.0
2 - No	1925	68.6	98.6
.a - Missing	40	1.4	100.0
Total	2806	100.0	

D33 Have you used a feeding tube? - *hn3_d33_sayh_feed_tube***Table 498:** 12-months - HN35: Have you used a feeding tube?

12M - Have you used a feeding tube:	No.	Col %	Cum %
1 - Yes	252	9.0	9.0
2 - No	2511	89.5	98.5
.a - Missing	43	1.5	100.0
Total	2806	100.0	

D34 Have you lost weight? - *hn3_d34_sayh_lost_wght*

Table 499: 12-months - HN35: Have you lost weight?

12M - Have you lost weight:	No.	Col %	Cum %
1 - Yes	549	19.6	19.6
2 - No	2192	78.1	97.7
.a - Missing	65	2.3	100.0
Total	2806	100.0	

D35 Have you gained weight? - *hn3_d35_sayh_gained_wght*

Table 500: 12-months - HN35: Have you gained weight?

12M - Have you gained weight:	No.	Col %	Cum %
1 - Yes	732	26.1	26.1
2 - No	1962	69.9	96.0
.a - Missing	112	4.0	100.0
Total	2806	100.0	

5.2.6 Your Feelings

The topics covered in the ‘Your Feelings’ questionnaire are based on the ‘Hospital Anxiety and Depression Scale (HADS)’ questionnaire (Zigmond and Snaith, 1983). Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

E1 I feel tense or 'wound up': - *hn3_e1_yf_tense*

Table 501: 12-months - HADS: I feel tense or 'wound up'

12M - I feel tense or wound up:	No.	Col %	Cum %
1 - Most of the time	130	4.6	4.6
2 - A lot of the time	327	11.7	16.3
3 - From time to time occasionally	1526	54.4	70.7
4 - Not at all	793	28.3	98.9
.a - Missing	30	1.1	100.0
Total	2806	100.0	

E2 I still enjoy the things I used to enjoy: - *hn3_e2_yf_enjoy*

Table 502: 12-months - HADS: I still enjoy the things I used to enjoy

12M - I still enjoy the things I used to enjoy:	No.	Col %	Cum %
1 - Definitely as much	1106	39.4	39.4
2 - Not quite so much	1215	43.3	82.7
3 - Only a little	282	10.0	92.8
4 - Hardly at all	169	6.0	98.8
.a - Missing	34	1.2	100.0
Total	2806	100.0	

E3 I get a sort of frightened feeling as if something awful is about to happen: - *hn3_e3_yf_frightened*

Table 503: 12-months - HADS: I get a sort of frightened feeling as if something awful is about to happen

12M - I get a sort of frightened feeling as if something awful is about to happe	No.	Col %	Cum %
1 - Very definitely and quite badly	160	5.7	5.7
2 - Yes but not to badly	514	18.3	24.0
3 - A little but it does not worry me	883	31.5	55.5
4 - Not at all	1220	43.5	99.0
.a - Missing	29	1.0	100.0
Total	2806	100.0	

E4 I can laugh and see the funny side of things: - *hn3_e4_yf_laugh*

Table 504: 12-months - HADS: I can laugh and see the funny side of things

12M - I can laugh and see the funny side of things:	No.	Col %	Cum %
1 - As much as I always could	1959	69.8	69.8
2 - Not quite so much now	636	22.7	92.5
3 - Definitely not so much now	152	5.4	97.9
4 - Not at all	33	1.2	99.1
.a - Missing	26	0.9	100.0
Total	2806	100.0	

E5 Worrying thoughts go through my mind: - *hn3_e5_yf_worrying***Table 505:** 12-months - HADS: Worrying thoughts go through my mind

12M - Worrying thoughts go through my mind:	No.	Col %	Cum %
1 - A great deal of the time	175	6.2	6.2
2 - A lot of the time	444	15.8	22.1
3 - From time to time but not too often	1072	38.2	60.3
4 - Only occasionally	1074	38.3	98.5
.a - Missing	41	1.5	100.0
Total	2806	100.0	

E6 I feel cheerful: - *hn3_e6_yf_cheerful***Table 506:** 12-months - HADS: I feel cheerful

12M - I feel cheerful:	No.	Col %	Cum %
1 - Not at all	44	1.6	1.6
2 - Not often	221	7.9	9.4
3 - Sometimes	772	27.5	37.0
4 - Most of the time	1737	61.9	98.9
.a - Missing	32	1.1	100.0
Total	2806	100.0	

E7 I can sit at ease and feel relaxed: - *hn3_e7_yf_at_ease***Table 507:** 12-months - HADS: I can sit at ease and feel relaxed

12M - I can sit at ease and feel relaxed:	No.	Col %	Cum %
1 - Definitely	982	35.0	35.0
2 - Usually	1325	47.2	82.2
3 - Not Often	421	15.0	97.2
4 - Not at all	44	1.6	98.8
.a - Missing	34	1.2	100.0
Total	2806	100.0	

E8 I feel as if I am slowed down: - *hn3_e8_yf_slowed***Table 508:** 12-months - HADS: I feel as if I am slowed down

12M - I feel as if I am slowed down:	No.	Col %	Cum %
1 - Nearly all the time	399	14.2	14.2
2 - Very often	613	21.8	36.1
3 - Sometimes	1252	44.6	80.7
4 - Not at all	506	18.0	98.7
.a - Missing	36	1.3	100.0
Total	2806	100.0	

E9 I get a sort of frightened feeling like 'butterflies' in the stomach: - *hn3_e9_yf_butterflies*

Table 509: 12-months - HADS: I get a sort of frightened feeling like 'butterflies' in the stomach

12M - I get a sort of frightened feeling like butterflies in the stomach:	No.	Col %	Cum %
1 - Not at all	1529	54.5	54.5
2 - Occasionally	1009	36.0	90.4
3 - Quite often	188	6.7	97.1
4 - Very often	46	1.6	98.8
.a - Missing	34	1.2	100.0
Total	2806	100.0	

E10 I have lost interest in my appearance: - *hn3_e10_yf_appearance*

Table 510: 12-months - HADS: I have lost interest in my appearance

12M - I have lost interest in my appearance:	No.	Col %	Cum %
1 - Definitely	80	2.9	2.9
2 - I don't take as much care as I should	304	10.8	13.7
3 - I may not take quite as much care	586	20.9	34.6
4 - I take just as much care as ever	1803	64.3	98.8
.a - Missing	33	1.2	100.0
Total	2806	100.0	

E11 I feel restless as I have to be on the move: - *hn3_e11_yf_restless*

Table 511: 12-months - HADS: I feel restless as I have to be on the move

12M - I feel restless as I have to be on the move:	No.	Col %	Cum %
1 - Very much indeed	144	5.1	5.1
2 - Quite a lot	686	24.4	29.6
3 - Not very much	1052	37.5	67.1
4 - Not at all	891	31.8	98.8
.a - Missing	33	1.2	100.0
Total	2806	100.0	

E12 I look forward with enjoyment to things: - *hn3_e12_yf_enjoyment*

Table 512: 12-months - HADS: I look forward with enjoyment to things

12M - I look forward with enjoyment to things:	No.	Col %	Cum %
1 - As much as I ever did	1486	53.0	53.0
2 - Rather less than I used to	823	29.3	82.3
3 - Definitely less than I used to	363	12.9	95.2
4 - Hardly at all	101	3.6	98.8
.a - Missing	33	1.2	100.0
Total	2806	100.0	

E13 I get sudden feelings of panic: - *hn3_e13_yf_panic*

Table 513: 12-months - HADS: I get sudden feelings of panic

12M - I get sudden feelings of panic:	No.	Col %	Cum %
1 - Very often indeed	76	2.7	2.7
2 - Quite often	270	9.6	12.3
3 - Not very often	952	33.9	46.3
4 - Not at all	1465	52.2	98.5
.a - Missing	43	1.5	100.0
Total	2806	100.0	

E14 I can enjoy a good book or radio or TV program: - *hn3_e14_yf_book*

Table 514: 12-months - HADS: I can enjoy a good book or radio or TV program

12M - I can enjoy a good book or radio or TV program:	No.	Col %	Cum %
1 - Often	1934	68.9	68.9
2 - Sometimes	572	20.4	89.3
3 - Not often	153	5.5	94.8
4 - Very seldom	103	3.7	98.4
.a - Missing	44	1.6	100.0
Total	2806	100.0	

5.2.7 Your Diet

F1 In summary, how many servings of fruit do you usually eat, not counting juices? - *hn3_f1_yd_servings_fruit*

Table 515: 12-months - YD: How many servings of fruit do you usually eat, not counting juices?

12M - How many servings of fruit do you usually eat	No.	Col %	Cum %
1 - None	278	9.9	9.9
2 - Less than one per month	132	4.7	14.6
3 - 1-3per month	196	7.0	21.6
4 - 1 per week	202	7.2	28.8
5 - 2-4 per week	564	20.1	48.9
6 - 5-6 per week	196	7.0	55.9
7 - 1 per day	392	14.0	69.9
8 - 2-3 per day	614	21.9	91.7
9 - 4-5 per day	126	4.5	96.2
10 - 6 or more per day	31	1.1	97.3
.a - Missing	75	2.7	100.0
Total	2806	100.0	

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

- *hn3_f2_yd_servings_veg*

Table 516: 12-months - YD: How many servings of vegetables do you usually eat, not counting salad or potatoes?

12M - How many servings of vegetables do you usually eat	No.	Col %	Cum %
1 - None	142	5.1	5.1
2 - Less than one per month	41	1.5	6.5
3 - 1-3per month	49	1.7	8.3
4 - 1 per week	102	3.6	11.9
5 - 2-4 per week	564	20.1	32.0
6 - 5-6 per week	372	13.3	45.3
7 - 1 per day	383	13.6	58.9
8 - 2-3 per day	927	33.0	91.9
9 - 4-5 per day	147	5.2	97.2
10 - 6 or more per day	21	0.7	97.9
.a - Missing	58	2.1	100.0
Total	2806	100.0	

F3 In summary, how often do you eat deep fried food (e.g. French fries, fried chicken, fried fish, fried clams, fried shrimp etc.)? - *hn3_f3_yd_deepfried_food*

Table 517: 12-months - YD: How often do you eat deep fried food?

12M - How often do you eat deep fried food	No.	Col %	Cum %
1 - Never	694	24.7	24.7
2 - Less than once per week	919	32.8	57.5
3 - Once per week	699	24.9	82.4
4 - 2-4 times per week	399	14.2	96.6
5 - 5-6 times per week	23	0.8	97.4
6 - Daily	8	0.3	97.7
.a - Missing	64	2.3	100.0
Total	2806	100.0	

5.2.8 You and Cancer

The topics covered in the ‘You and Cancer’ questionnaire are based on the ‘Fears of Recurrence’ questionnaire (Humphris and Ozakinci, 2008). Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

G1 I am afraid my cancer may recur - *hn3_g1_yc_cancer_recur*

Table 518: 12-months - YC: I am afraid my cancer may recur

12M - I am afraid that my cancer may recur:	No.	Col %	Cum %
1 - Not at all	315	11.2	11.2
2 - A little	915	32.6	43.8
3 - Sometimes	922	32.9	76.7
4 - A lot	420	15.0	91.7
5 - All the time	187	6.7	98.3
.a - Missing	47	1.7	100.0
Total	2806	100.0	

G2 I am worried about the possibility of cancer recurrence - *hn3_g2_yc_recurrence*

Table 519: 12-months - YC: I am worried about the possibility of cancer recurrence

12M - I am worried about the possibility of cancer recurrence:	No.	Col %	Cum %
1 - Not at all	285	10.2	10.2
2 - A little	971	34.6	44.8
3 - Sometimes	866	30.9	75.6
4 - A lot	445	15.9	91.5
5 - All the time	177	6.3	97.8
.a - Missing	62	2.2	100.0
Total	2806	100.0	

G3 How often have you worried about the possibility of getting cancer again? - *hn3_g3_yc_how_often*

Table 520: 12-months - YC: How often have you worried about the possibility of getting cancer again?

12M - How often have you worried about the possibility of getting cancer again:	No.	Col %	Cum %
1 - Not at all	209	7.4	7.4
2 - A little	550	19.6	27.0
3 - Sometimes	1232	43.9	71.0
4 - A lot	565	20.1	91.1
5 - All the time	193	6.9	98.0
.a - Missing	57	2.0	100.0
Total	2806	100.0	

G4 I get waves of strong feelings about the cancer coming back - *hn3_g4_yc_strong_feel*

Table 521: 12-months - YC: I get waves of strong feelings about the cancer coming back

12M - I get waves of strong feelings about the cancer coming back:	No.	Col %	Cum %
1 - Not at all	976	34.8	34.8
2 - A little	701	25.0	59.8
3 - Sometimes	622	22.2	81.9
4 - A lot	291	10.4	92.3
5 - All the time	152	5.4	97.7
.a - Missing	64	2.3	100.0
Total	2806	100.0	

5.2.9 Your Personal Costs

H1a Paid for any kind of medication? - *hn3_h1a_ypc_paid_med***Table 522:** 12-months - YPC: Paid for any kind of medication?

12M - Paid for any kind of medication:	No.	Col %	Cum %
1 - Yes	321	11.4	11.4
2 - No	1886	67.2	78.7
3 - N/A	464	16.5	95.2
.a - Missing	135	4.8	100.0
Total	2806	100.0	

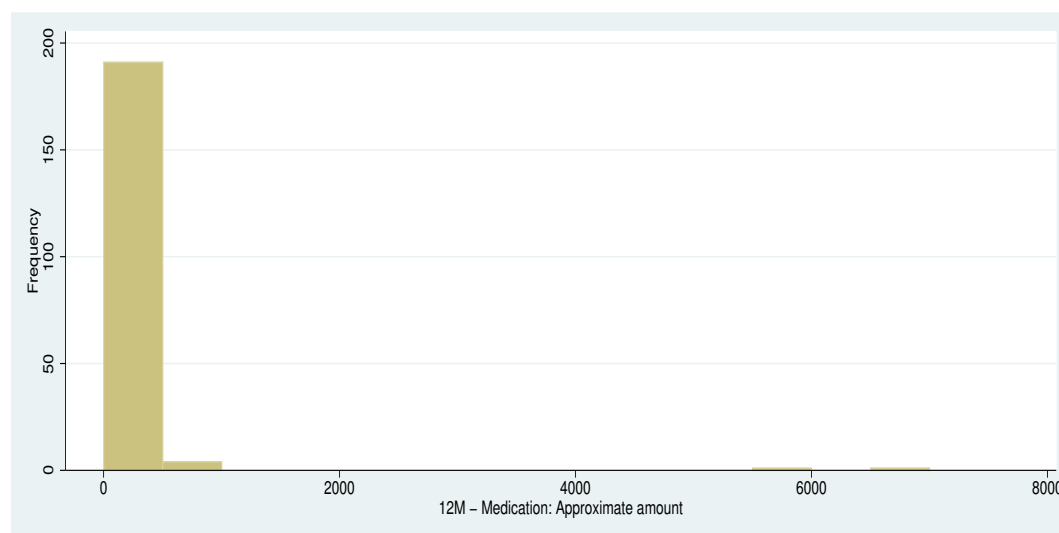
H1b Types of medication - *hn3_h1b_ypc_type_med*

- This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

H1c Paid for any kind of medication, approximate amount - *hn3_h1c_ypc_med_cost*

Descriptives:

- Total valid responses = 197, number of missing values or data check errors = 124

Figure 80: 12-months - YPC: Paid for any kind of treatment, approximate amount

H2a Paid for any kind of treatment - *hn3_h2a_ypc_paid_treat***Table 523:** 12-months - YPC: Paid for any kind of treatment

12M - Paid for any kind of treatment, ie private health care:	No.	Col %	Cum %
1 - Yes	218	7.8	7.8
2 - No	2064	73.6	81.3
3 - N/A	408	14.5	95.9
.a - Missing	116	4.1	100.0
Total	2806	100.0	

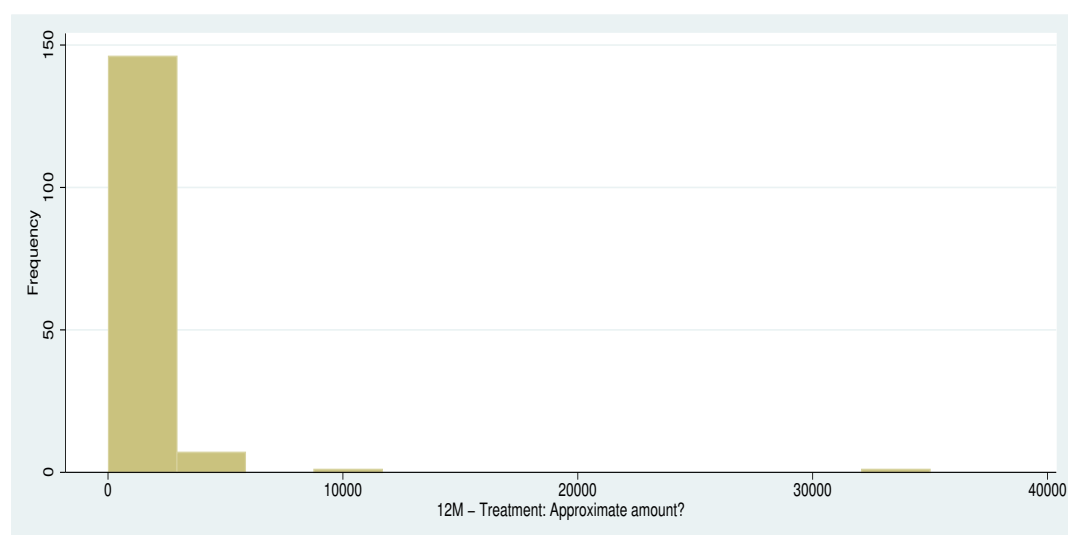
H2b Types of treatment - *hn3_h2b_ypc_type_treat*

- This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

H2c Paid for any kind of treatment, approximate amount - *hn3_h2c_ypc_treat_cost*

Descriptives:

- Total valid responses = 155, number of missing values or data check errors = 63

Figure 81: 12-months - YPC: Paid for any kind of treatment, approximate amount

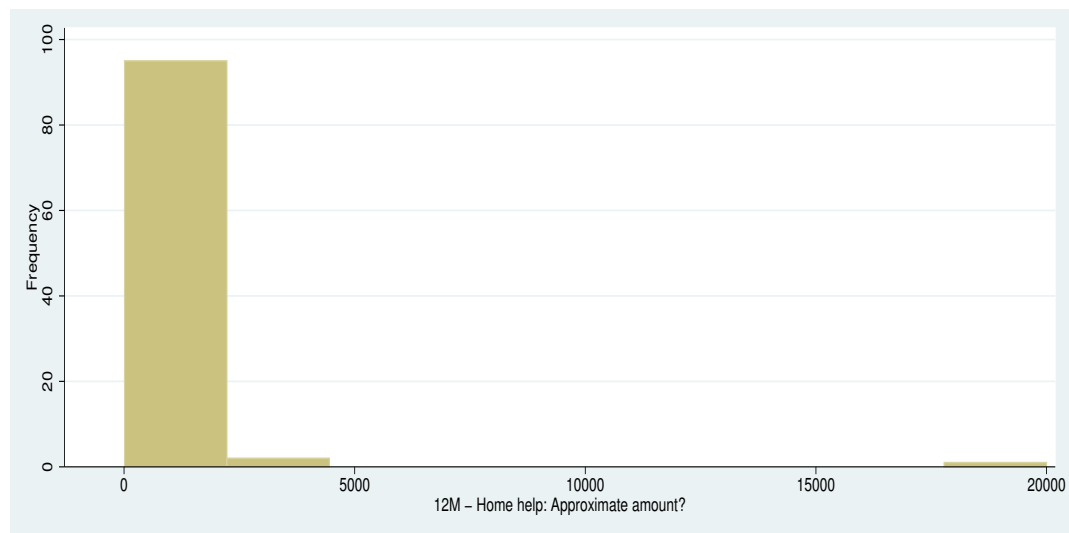
H3a Paid for home help - *hn3_h3a_ypc_home_hlp***Table 524:** 12-months - YPC: Paid for home help

12M - Paid for home help:	No.	Col %	Cum %
1 - Yes	141	5.0	5.0
2 - No	2132	76.0	81.0
3 - N/A	412	14.7	95.7
.a - Missing	121	4.3	100.0
Total	2806	100.0	

H3b Paid for home help, approximate amount - *hn3_h3b_ypc_cost_home_hlp*

Descriptives:

- Total valid responses = 98, number of missing values or data check errors = 43

Figure 82: 12-months - YPC: Paid for home help, approximate amount

H4a Incurred any travel expenses for your hospital/clinic appointments? - *hn3_h4a_ypc_travel_cost*

Table 525: 12-months - YPC: Incurred any travel expenses for your hospital/clinic appointments?

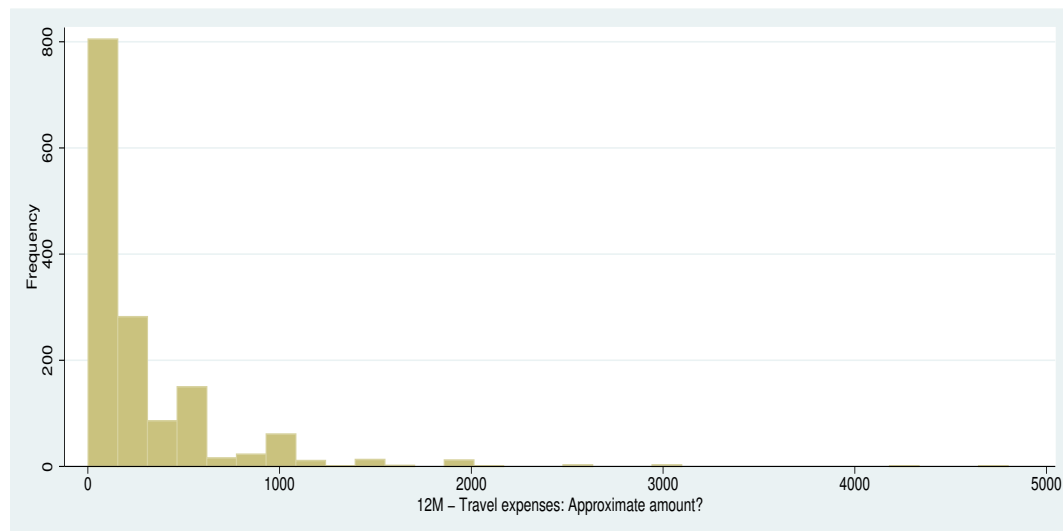
12M - Incurred any travel expenses for your hospital/clinic appointments? (eg tr	No.	Col %	Cum %
1 - Yes	1802	64.2	64.2
2 - No	629	22.4	86.6
3 - N/A	217	7.7	94.4
.a - Missing	158	5.6	100.0
Total	2806	100.0	

H4b Incurred any travel expenses for your hospital/clinic appointments?, approximate amount - *hn3_h4b_ypc_cost_travel*

Descriptives:

- Total valid responses = 1471, number of missing values or data check errors = 331

Figure 83: 12-months - YPC: Incurred any travel expenses for your hospital/clinic appointments?, approximate amount



H5a Incurred any other out-of-pocket expenses - *hn3_h5a_ypc_out_of_pocket***Table 526:** 12-months - YPC: Incurred any other out-of-pocket expenses

12M - Incurred any other out-of-pocket expenses? (e.g. special dietary items, pa	No.	Col %	Cum %
1 - Yes	313	11.2	11.2
2 - No	1960	69.9	81.0
3 - N/A	330	11.8	92.8
.a - Missing	203	7.2	100.0
Total	2806	100.0	

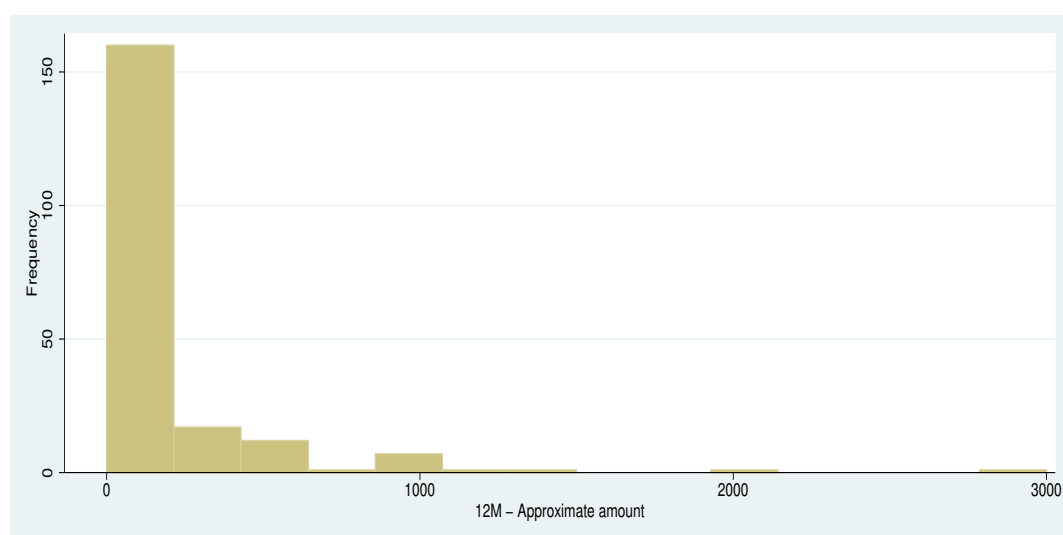
H5b Types of expenditure - *hn3_h5b_ypc_type_expend*

- This is a free-text variable and has not been coded or categorised at present. Raw data is available on request.

H5c Incurred any other out-of-pocket expenses, approximate amount - *hn3_h5c_ypc_expend_cost*

Descriptives:

- Total valid responses = 201, number of missing values or data check errors = 112

Figure 84: 12-months - YPC: Incurred any other out-of-pocket expenses, approximate amount

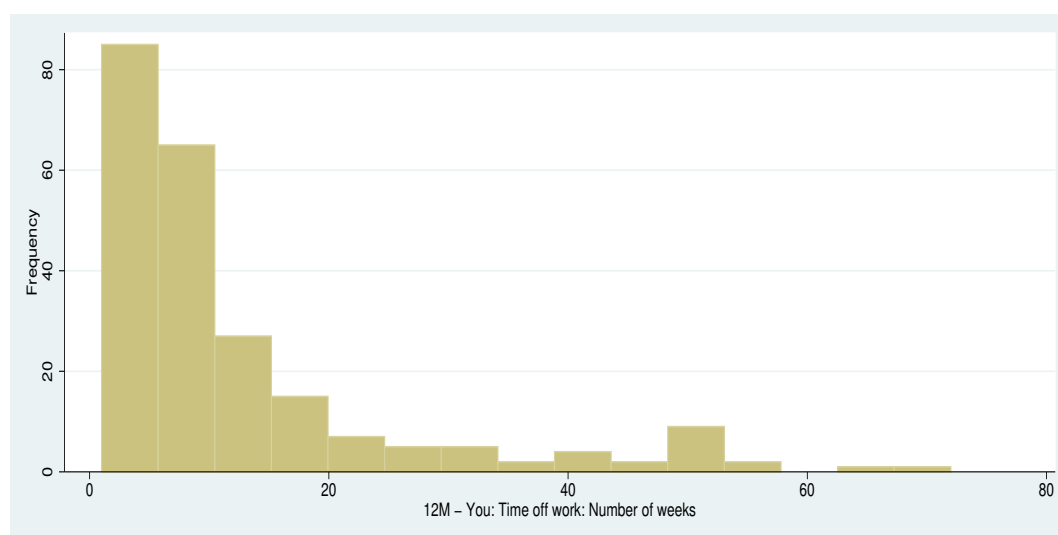
H6a Have you taken time off work because of your illness? - *hn3_h6a_ypc_offwork***Table 527:** 12-months - YPC: Have you taken time off work because of your illness?

12M - Have you taken time off work because of your illness:	No.	Col %	Cum %
1 - Yes	1185	42.2	42.2
2 - No	862	30.7	73.0
3 - N/A	626	22.3	95.3
.a - Missing	133	4.7	100.0
Total	2806	100.0	

H6b Number of weeks - *hn3_h6b_ypc_offwork_wks*

Descriptives:

- Total valid responses = 230, number of missing values or data check errors = 955

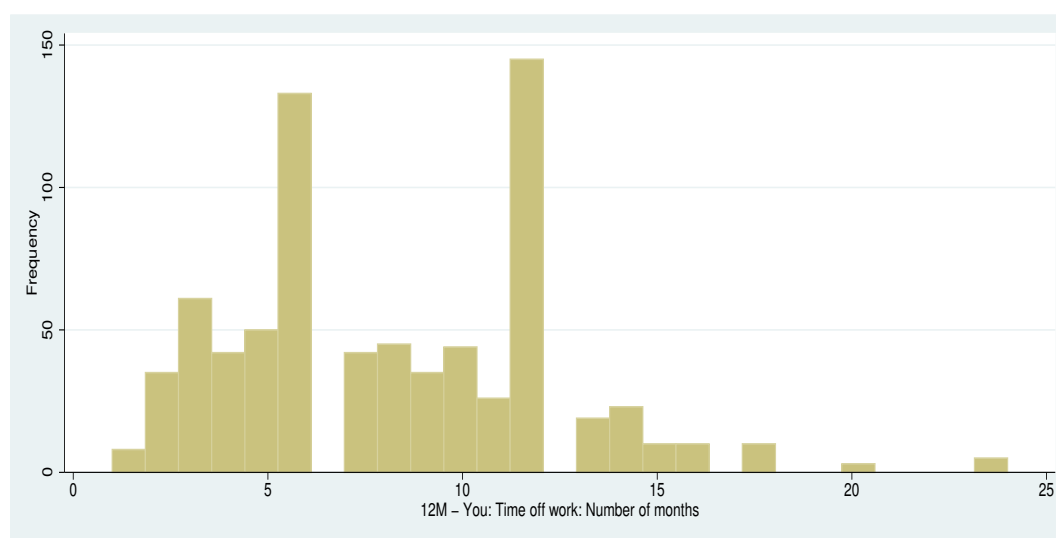
Figure 85: 12-months - YPC: Have you taken time off work because of your illness? Number of weeks

H6c Number of months - *hn3_h6c_ypc_offwork_mths*

Descriptives:

- Total valid responses = 746, number of missing values or data check errors = 439

Figure 86: 12-months - YPC: Have you taken time off work because of your illness? Number of months



H7a Has a member of your immediate family taken time off work because of your illness? -
hn3_h7a_ypc_fam_offwork

Table 528: 12-months - YPC: Has a member of your immediate family taken time off work because of your illness?

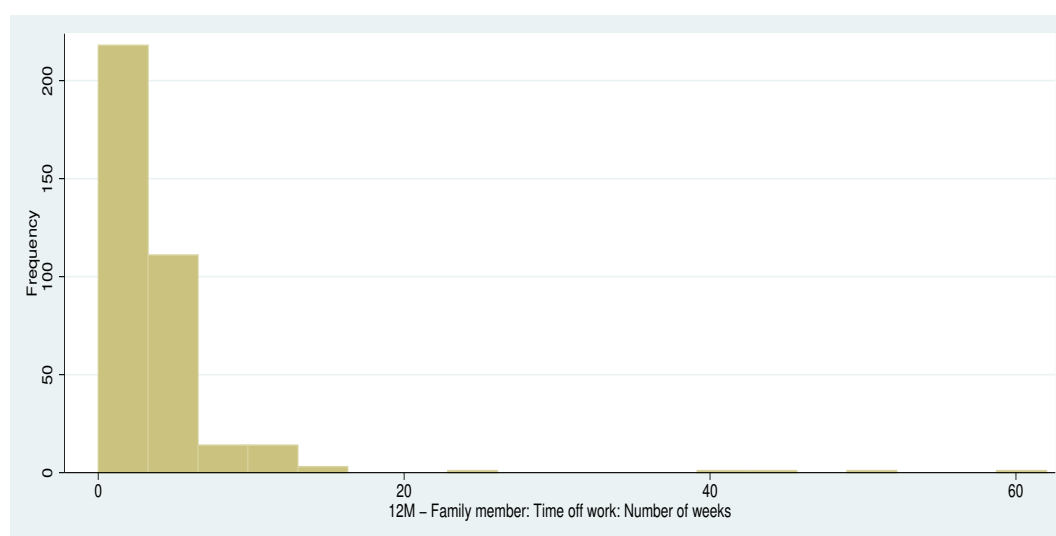
12M - Has a member of your immediate family taken time off work because of your	No.	Col %	Cum %
1 - Yes	779	27.8	27.8
2 - No	1473	52.5	80.3
3 - N/A	419	14.9	95.2
.a - Missing	135	4.8	100.0
Total	2806	100.0	

H7b Number of weeks - *hn3_h7b_ypc_fam_offwork_wks*

Descriptives:

- Total valid responses = 365, number of missing values or data check errors = 414

Figure 87: 12-months - YPC: Has a member of your immediate family taken time off work because of your illness? Number of weeks

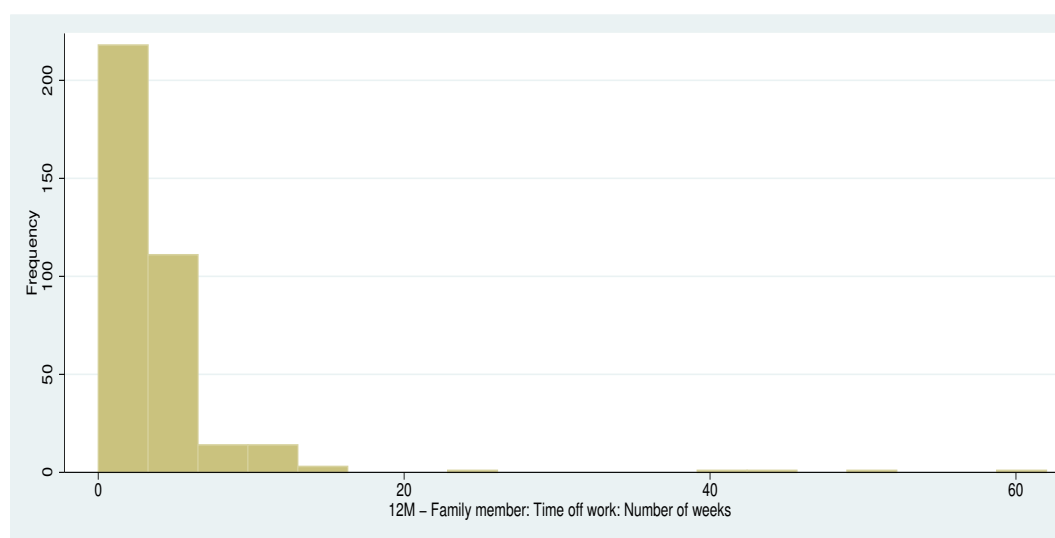


H7c Number of months - *hn3_h7c_ypc_fam_offwork_mths*

Descriptives:

- Total valid responses = 365, number of missing values or data check errors = 414

Figure 88: 12-months - YPC: Has a member of your immediate family taken time off work because of your illness? Number of months



H8a Have you suffered any reduction of income as a result of taking time off work because of your illness? - *hn3_h8a_ypc_reduce_inc*

Table 529: 12-months - YPC: Have you suffered any reduction of income as a result of taking time off work because of your illness?

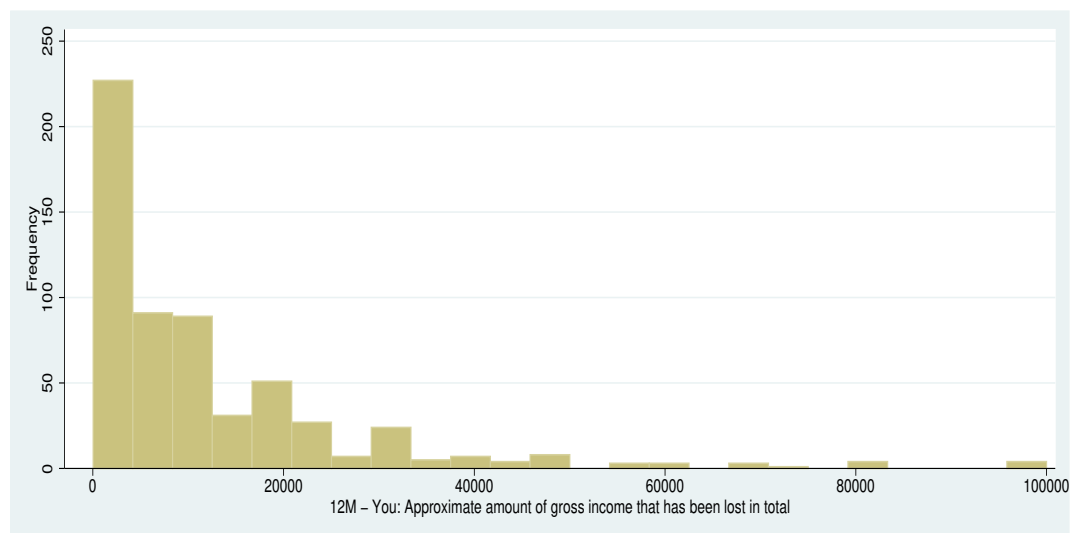
12M - Have you suffered any reduction of income as a result of taking time off w	No.	Col %	Cum %
1 - Yes	794	28.3	28.3
2 - No	1295	46.2	74.4
3 - N/A	564	20.1	94.5
.a - Missing	153	5.5	100.0
Total	2806	100.0	

H8b Approximate amount of gross income that has been lost in total - *hn3_h8b_ypc_gross_inc*

Descriptives:

- Total valid responses = 589, number of missing values or data check errors = 205

Figure 89: 12-months - YPC: Approximate amount of gross income that has been lost in total.



H9a Has any member of your immediate family suffered any reduction of income as a result of taking time off work because of your illness? - *hn3_h9a_ypc_fam_reduce_inc*

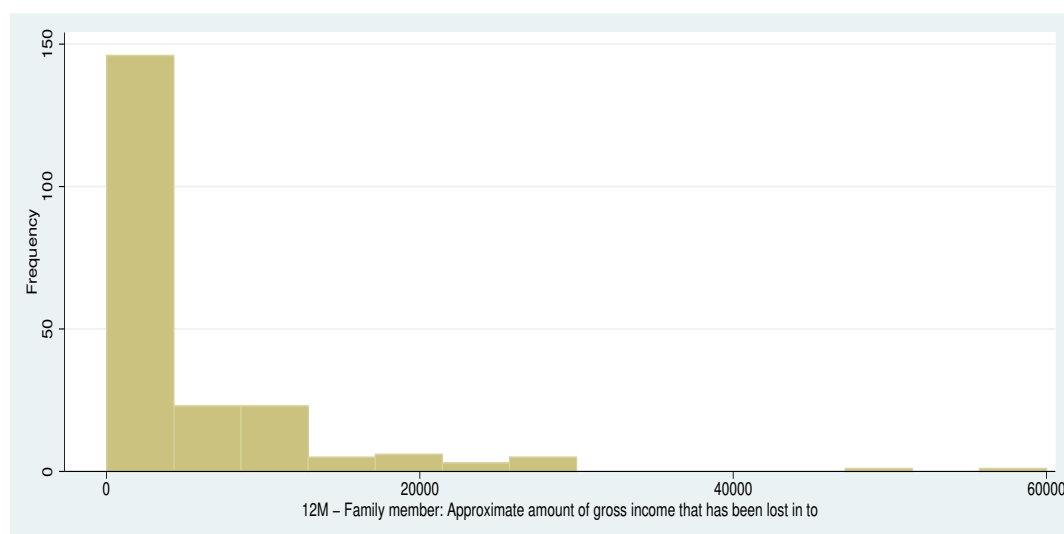
Table 530: 12-months - YPC: Has any member of your immediate family suffered any reduction of income as a result of taking time off work because of your illness?

12M - Has any member of your immediate family suffered any reduction of income a	No.	Col %	Cum %
1 - Yes	333	11.9	11.9
2 - No	1840	65.6	77.4
3 - N/A	471	16.8	94.2
.a - Missing	162	5.8	100.0
Total	2806	100.0	

H9b Approximate amount of gross income that has been lost in total - *hn3_h9b_ypc_fam_gross_inc*
Descriptives:

- Total valid responses = 213, number of missing values or data check errors = 120

Figure 90: 12-months - YPC: Approximate amount of gross income that has been lost in total.



H10a Have you given up work completely because of your illness? - *hn3_h10a_ypc_stop_work*

Table 531: 12-months - YPC: Have you given up work completely because of your illness?

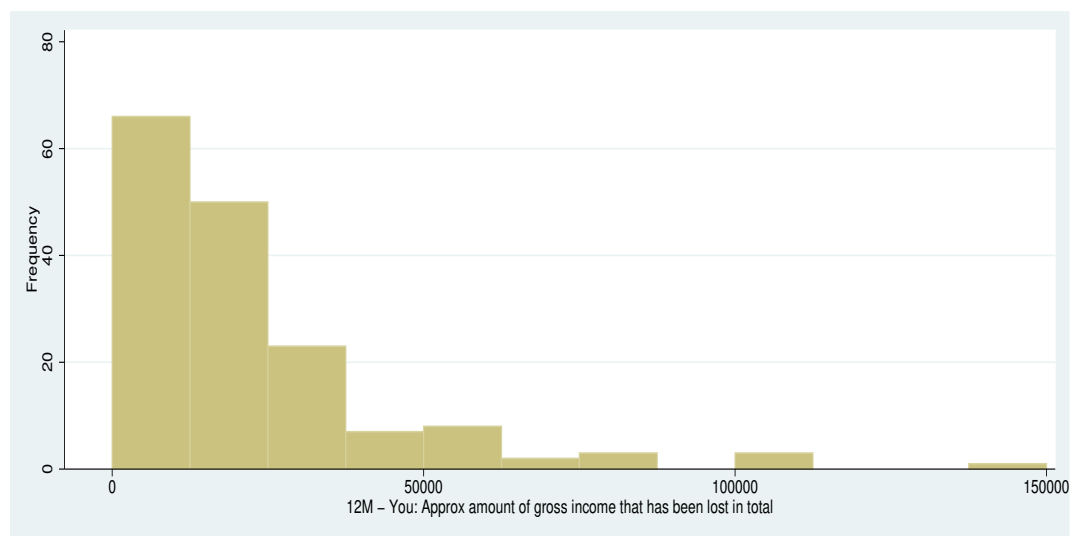
12M - You: Have you given up work completely because of your illness?:	No.	Col %	Cum %
1 - Yes	374	13.3	13.3
2 - No	1556	55.5	68.8
3 - N/A	581	20.7	89.5
.a - Missing	295	10.5	100.0
Total	2806	100.0	

H10b Approximate amount of gross income that has been lost in total - *hn3_h10b_ypc_lost_inc*

Descriptives:

- Total valid responses = 163, number of missing values or data check errors = 211

Figure 91: 12-months - YPC: Approximate amount of gross income that has been lost in total.



H11a Has any member of your immediate family given up work completely because of your illness? - *hn3_h11a_ypc_fam_stop_work*

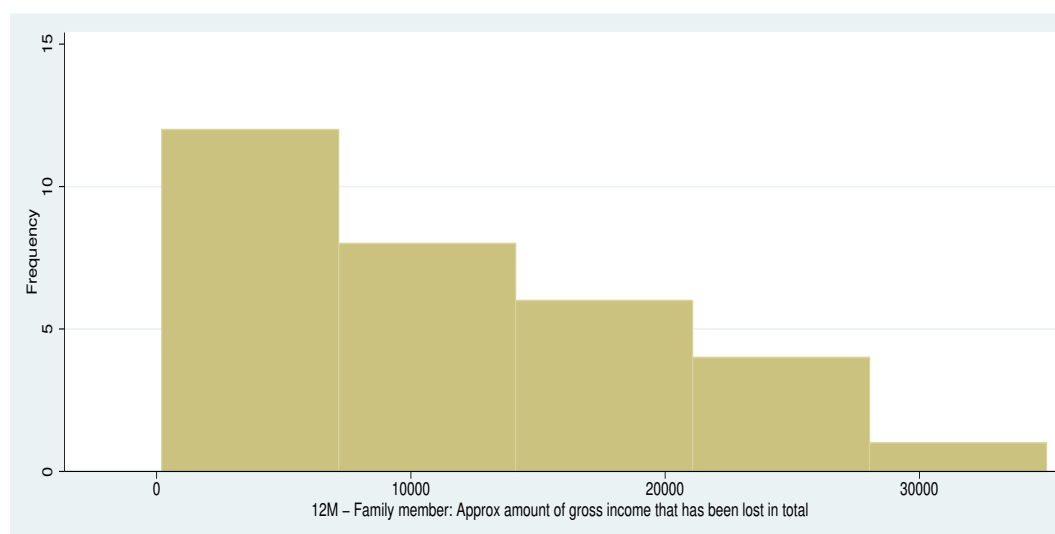
Table 532: 12-months - YPC: Has any member of your immediate family given up work completely because of your illness?

12M - Has any member of your immediate family given up work completely because o	No.	Col %	Cum %
1 - Yes	90	3.2	3.2
2 - No	2029	72.3	75.5
3 - N/A	433	15.4	90.9
.a - Missing	254	9.1	100.0
Total	2806	100.0	

H11b Approximate amount of gross income that has been lost in total - *hn3_h11b_ypc_fam_lost_inc*
Descriptives:

- Total valid responses = 31, number of missing values or data check errors = 59

Figure 92: 12-months - YPC: Approximate amount of gross income that has been lost in total.



H12a Have you run into difficulties with paying the mortgage or rent for the property where you live? - *hn3_h12a_ypc_diffi_mortgage*

Table 533: 12-months - YPC: Have you run into difficulties with paying the mortgage or rent for the property where you live?

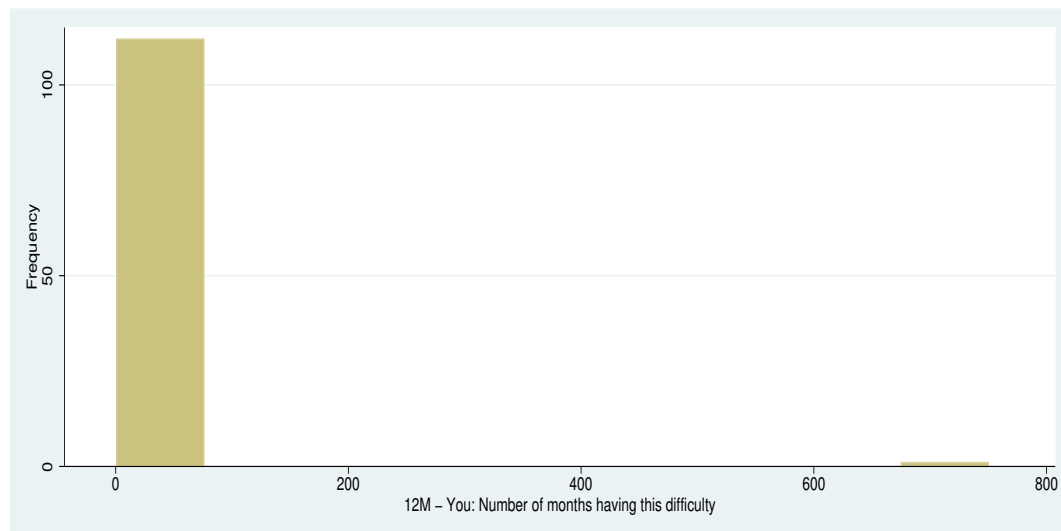
12M - Have you run into difficulties with paying the mortgage or rent for the pr	No.	Col %	Cum %
1 - Yes	200	7.1	7.1
2 - No	1929	68.7	75.9
3 - N/A	418	14.9	90.8
.a - Missing	259	9.2	100.0
Total	2806	100.0	

H12b Number of months having this difficulty - *hn3_h12b_ypc_no_months*

Descriptives:

- Total valid responses = 113, number of missing values or data check errors = 87

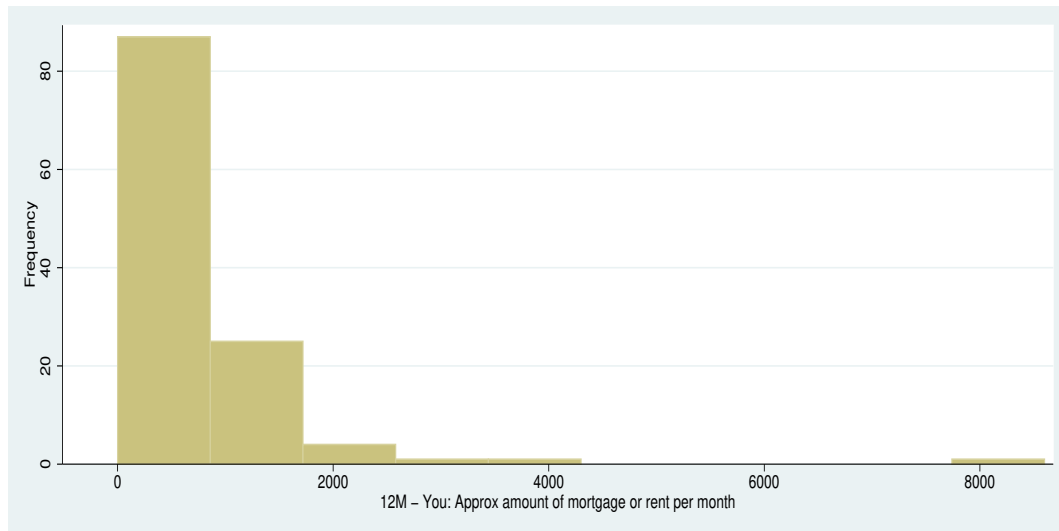
Figure 93: 12-months - YPC: Number of months having this difficulty



H12c Approximate amount of mortgage or rent per month - *hn3_h12c_ypc_mortg_rent_amo*

Descriptives:

- Total valid responses = 119, number of missing values or data check errors = 81

Figure 94: 12-months - YPC: Approximate amount of mortgage or rent per month

5.2.10 Your Quality of Life

The topics covered in the ‘Your Quality of Life’ questionnaire are based on the revised ‘University of Washington (UW) QoL’ questionnaire (Hassan and Weymuller, 1993; Rogers et al., 2002). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

I1 Pain - *hn3_i1_yql_pain***Table 534:** 12-months - UWQoL - Pain

12M - Pain:	No.	Col %	Cum %
1 - I have no pain	107	42.5	42.5
2 - There is mild pain not needing medication	76	30.2	72.6
3 - I have moderate pain(reg medication)	45	17.9	90.5
4 - I have severe pain controlled only by prescription medicine	17	6.7	97.2
5 - I have severe pain not controlled by medication	3	1.2	98.4
.a - Missing	4	1.6	100.0
Total	252	100.0	

I2 Appearance - *hn3_i2_yql_appearance***Table 535:** 12-months - UWQoL - Appearance

12M - Appearance	No.	Col %	Cum %
1 - There is no change in my appearance	81	32.1	32.1
2 - The change in my appearance is minor	126	50.0	82.1
3 - My appearance bothers me but I remain active	40	15.9	98.0
4 - I feel significantly disfigured and limit my activities due to my appearance	3	1.2	99.2
.a - Missing	2	0.8	100.0
Total	252	100.0	

I3 Activity - *hn3_i3_yql_activity***Table 536:** 12-months - UWQoL - A

12M - Activity	No.	Col %	Cum %
1 - I am as active as I have ever been	68	27.0	27.0
2 - There are times when I cannot keep up my old pace but not often	87	34.5	61.5
3 - I am often tired and have slowed down my activities although I still get out	87	34.5	96.0
4 - I donot go out because I donot have the strength	7	2.8	98.8
5 - I am usually in bed or chair and donot leave home	1	0.4	99.2
.a - Missing	2	0.8	100.0
Total	252	100.0	

I4 Recreation - *hn3_i4_yql_recreation***Table 537:** 12-months - UWQoL - Recreation

12M - Recreation	No.	Col %	Cum %
1 - There are no limitations to recreation at home or away from home	84	33.3	33.3
2 - There are a few things I cannot do but I still get out and enjoy life	112	44.4	77.8
3 - There are many times when I wish I could get out more but I am not up to it	41	16.3	94.0
4 - There are severe limitations to what I can do mostly I stay at home and watch TV	9	3.6	97.6
5 - I cannot do anything enjoyable	3	1.2	98.8
.a - Missing	3	1.2	100.0
Total	252	100.0	

I5 Swallowing - *hn3_i5_yql_swallowing***Table 538:** 12-months - UWQoL - Swallowing

12M - Swallowing:	No.	Col %	Cum %
1 - I can swallow as well as ever	115	45.6	45.6
2 - I cannot swallow certain solid foods	116	46.0	91.7
3 - I can only swallow liquid food	9	3.6	95.2
4 - I cannot swallow because it goes down the wrong way and chokes me	5	2.0	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

I6 Chewing - *hn3_i6_yql_chewing***Table 539:** 12-months - UWQoL - Chewing

12M - Chewing:	No.	Col %	Cum %
1 - I can chew as well as ever	131	52.0	52.0
2 - I can eat soft solids but cannot chew some foods	105	41.7	93.7
3 - I cannot even chew soft solids	10	4.0	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

I7 Speech - *hn3_i7_yql_speech***Table 540:** 12-months - UWQoL - Speech

12M - Speech:	No.	Col %	Cum %
1 - My speech is the same as always	143	56.7	56.7
2 - I have difficulty with saying some words but I can be understood over the phone	89	35.3	92.1
3 - Only my family and friends can understand me	12	4.8	96.8
4 - Only my family and friends can understand me	1	0.4	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

I8 Shoulder - *hn3_i8_yql_shoulder***Table 541:** 12-months - UWQoL - Shoulder

12M - Shoulder	No.	Col %	Cum %
1 - I have no problem with my shoulder	164	65.1	65.1
2 - My shoulder is stiff but it has not affected my activity or strength	53	21.0	86.1
3 - Pain or weakness in my shoulder has caused me to change my work	27	10.7	96.8
4 - I cannot work due to problems with my shoulder	6	2.4	99.2
.a - Missing	2	0.8	100.0
Total	252	100.0	

I9 Taste - *hn3_i9_yql_taste***Table 542:** 12-months - UWQoL - Taste

12M - Taste:	No.	Col %	Cum %
1 - I can taste food normally	92	36.5	36.5
2 - I can taste most foods normally	73	29.0	65.5
3 - I can taste some foods	68	27.0	92.5
4 - I cannot taste any foods	12	4.8	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

I10 Saliva - *hn3_i10_yql_saliva***Table 543:** 12-months - UWQoL - Saliva

12M - Saliva:	No.	Col %	Cum %
1 - My saliva is of normal consistency	92	36.5	36.5
2 - I have less saliva than normal but it is enough	71	28.2	64.7
3 - I have too little saliva	67	26.6	91.3
4 - I have no saliva	11	4.4	95.6
.a - Missing	11	4.4	100.0
Total	252	100.0	

I11 Mood - *hn3_i11_yql_mood***Table 544:** 12-months - UWQoL - Mood

12M - Mood	No.	Col %	Cum %
1 - My mood is excellent and unaffected by my cancer	85	33.7	33.7
2 - My mood is generally good and only occasionally affected by my cancer	98	38.9	72.6
3 - I am neither in a good mood nor depressed about my cancer	32	12.7	85.3
4 - I am somewhat depressed about my cancer	26	10.3	95.6
5 - I am extremely depressed about my cancer	6	2.4	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

I12 Anxiety - *hn3_i12_yql_anxiety***Table 545:** 12-months - UWQoL - Anxiety

12M - Anxiety:	No.	Col %	Cum %
1 - I am not anxious about my cancer	81	32.1	32.1
2 - I am a little anxious about my cancer	129	51.2	83.3
3 - I am anxious about my cancer	29	11.5	94.8
4 - I am very anxious about my cancer	9	3.6	98.4
.a - Missing	4	1.6	100.0
Total	252	100.0	

I13A (1) Which issues have been the most important to you during the past 7 days? - *hn3_i13a_yql_issues*

Table 546: 12-months - UWQoL - (1) Which issues have been the most important to you during the past 7 days?

12M - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
1 - Pain	62	24.6	24.6
2 - Appearance	33	13.1	37.7
3 - Activity	30	11.9	49.6
4 - Recreation	12	4.8	54.4
5 - Swallowing	42	16.7	71.0
6 - Chewing	9	3.6	74.6
7 - Speech	7	2.8	77.4
8 - Shoulder	3	1.2	78.6
9 - Taste	5	2.0	80.6
10 - Saliva	7	2.8	83.3
11 - Mood	7	2.8	86.1
12 - Anxiety	4	1.6	87.7
.a - Missing	31	12.3	100.0
Total	252	100.0	

I13B (2) Which issues have been the most important to you during the past 7 days? - *hn3_i13b_yql_issues*

Table 547: 12-months - UWQoL - (2) Which issues have been the most important to you during the past 7 days?

12M - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
2 - Appearance	3	1.2	1.2
3 - Activity	16	6.3	7.5
4 - Recreation	10	4.0	11.5
5 - Swallowing	28	11.1	22.6
6 - Chewing	24	9.5	32.1
7 - Speech	20	7.9	40.1
8 - Shoulder	26	10.3	50.4
9 - Taste	23	9.1	59.5
10 - Saliva	16	6.3	65.9
11 - Mood	11	4.4	70.2
12 - Anxiety	10	4.0	74.2
.a - Missing	65	25.8	100.0
Total	252	100.0	

I13C (3) Which issues have been the most important to you during the past 7 days? - *hn3_i13c_yql_issues*

Table 548: 12-months - UWQoL - (3) Which issues have been the most important to you during the past 7 days?

12M - Which issues have been the most important to you during the past 7 days:	No.	Col %	Cum %
4 - Recreation	5	2.0	2.0
5 - Swallowing	1	0.4	2.4
6 - Chewing	6	2.4	4.8
7 - Speech	13	5.2	9.9
8 - Shoulder	3	1.2	11.1
9 - Taste	25	9.9	21.0
10 - Saliva	54	21.4	42.5
11 - Mood	20	7.9	50.4
12 - Anxiety	24	9.5	59.9
.a - Missing	101	40.1	100.0
Total	252	100.0	

I14 In general, would you say your health-related quality of life during the past 7 days has been: - *hn3_i14_yql_qol_month*

Table 549: 12-months - UWQoL - In general, would you say your health-related quality of life during the past 7 days has been:

12M - Compared to the month before you developed cancer, how would you rate your	No.	Col %	Cum %
1 - Much better	25	9.9	9.9
2 - Somewhat better	25	9.9	19.8
3 - About the same	101	40.1	59.9
4 - Somewhat worse	78	31.0	90.9
5 - Much worse	18	7.1	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

I15 In general, would you say your health-related quality of life during the past 7 days has been: - *hn3_i15_yql_qol_7_days*

Table 550: 12-months - UWQoL - In general, would you say your health-related quality of life during the past 7 days has been:

12M - In general, would you say your health-related quality of life during the	No.	Col %	Cum %
1 - Outstanding	8	3.2	3.2
2 - Very good	70	27.8	31.0
3 - Good	91	36.1	67.1
4 - Fair	59	23.4	90.5
5 - Poor	13	5.2	95.6
6 - Very Poor	6	2.4	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

I16 Overall quality of life during the past 7 days - *hn3_i16_yql_well_being***Table 551:** 12-months - UWQoL - Overall quality of life during the past 7 days

12M - Considering everything in your life that contributes to your personal well	No.	Col %	Cum %
1 - Outstanding	15	6.0	6.0
2 - Very good	75	29.8	35.7
3 - Good	85	33.7	69.4
4 - Fair	49	19.4	88.9
5 - Poor	14	5.6	94.4
6 - Very poor	3	1.2	95.6
.a - Missing	11	4.4	100.0
Total	252	100.0	

I17A 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. - *hn3_i17_yql_items*

5.2.11 Difficulties in Your Life

The topics covered in the ‘Difficulties in Your Life’ questionnaire are based on the ‘Social difficulties Inventory (SDI)’ questionnaire (Wright et al., 2005). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

J1 Have you had any difficulty maintaining your independence? - *hn3_j1_dyl_independence*

Table 552: 12-months - SDI - Have you had any difficulty maintaining your independence?

12M - Have you had any difficulty maintaining your independence:	No.	Col %	Cum %
1 - No difficulty	191	75.8	75.8
2 - A little	44	17.5	93.3
3 - Quite a bit	8	3.2	96.4
4 - Very much	3	1.2	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

J2 Have you had any difficulty in carrying out your domestic chores? - *hn3_j2_dyl_dom_chores*

Table 553: 12-months - SDI - Have you had any difficulty in carrying out your domestic chores?

12M - Have you had any difficulty in carrying out your domestic chores? (e.g. cl	No.	Col %	Cum %
1 - No difficulty	139	55.2	55.2
2 - A little	69	27.4	82.5
3 - Quite a bit	30	11.9	94.4
4 - Very much	9	3.6	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

J3 Have you had any difficulty with managing your own personal care? - *hn3_j3_dyl_personal_care*

Table 554: 12-months - SDI - Have you had any difficulty with managing your own personal care?

12M - Have you had any difficulty with managing your own personal care? (e.g. ba	No.	Col %	Cum %
1 - No difficulty	211	83.7	83.7
2 - A little	32	12.7	96.4
3 - Quite a bit	3	1.2	97.6
4 - Very much	3	1.2	98.8
.a - Missing	3	1.2	100.0
Total	252	100.0	

J4 Have you had any difficulty with looking after those who depend on you? - *hn3_j4_dyl_dependents*

Table 555: 12-months - SDI - Have you had any difficulty with looking after those who depend on you?

12M - Have you had any difficulty with looking after those who depend on you? (e	No.	Col %	Cum %
1 - No difficulty	199	79.0	79.0
2 - A little	26	10.3	89.3
3 - Quite a bit	4	1.6	90.9
4 - Very much	3	1.2	92.1
.a - Missing	20	7.9	100.0
Total	252	100.0	

J5 Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them? - *hn3_j5_dyl_support*

Table 556: 12-months - SDI - Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?

12M - Have any of those close to you (e.g. partner, children, parents) had any d	No.	Col %	Cum %
1 - No difficulty	209	82.9	82.9
2 - A little	22	8.7	91.7
3 - Quite a bit	2	0.8	92.5
4 - Very much	3	1.2	93.7
.a - Missing	16	6.3	100.0
Total	252	100.0	

J6 Have you had any difficulties with benefits? - *hn3_j6_dyl_benefits*

Table 557: 12-months - SDI - Have you had any difficulties with benefits?

12M - Have you had any difficulties with benefits? (e.g. statutory sick pay, att	No.	Col %	Cum %
1 - No difficulty	208	82.5	82.5
2 - A little	13	5.2	87.7
3 - Quite a bit	8	3.2	90.9
4 - Very much	10	4.0	94.8
.a - Missing	13	5.2	100.0
Total	252	100.0	

J7 Have you had any financial difficulties? - *hn3_j7_dyl_financial_dif*

Table 558: 12-months - SDI - Have you had any financial difficulties?

12M - Have you had any financial difficulties:	No.	Col %	Cum %
1 - No difficulty	181	71.8	71.8
2 - A little	41	16.3	88.1
3 - Quite a bit	10	4.0	92.1
4 - Very much	7	2.8	94.8
.a - Missing	13	5.2	100.0
Total	252	100.0	

J8 Have you had any difficulties with financial services? - *hn3_j8_dyl_financial_service*

Table 559: 12-months - SDI - Have you had any difficulties with financial services?

12M - Have you had any difficulties with financial services? (e.g. loans, mortga	No.	Col %	Cum %
1 - No difficulty	218	86.5	86.5
2 - A little	12	4.8	91.3
3 - Quite a bit	5	2.0	93.3
4 - Very much	7	2.8	96.0
.a - Missing	10	4.0	100.0
Total	252	100.0	

J9 Have you had any difficulty concerning your work? - *hn3_j9_dyl_difficulty_work*

Table 560: 12-months - SDI - Have you had any difficulty concerning your work?

12M - Have you had any difficulty concerning your work? (or education if you are	No.	Col %	Cum %
1 - No difficulty	186	73.8	73.8
2 - A little	29	11.5	85.3
3 - Quite a bit	8	3.2	88.5
4 - Very much	7	2.8	91.3
.a - Missing	22	8.7	100.0
Total	252	100.0	

J10 Have you had any difficulty with planning for your own or your family's future? - *hn3_j10_dyl_dif_plan_future*

Table 561: 12-months - SDI - Have you had any difficulty with planning for your own or your family's future?

12M - Have you had any difficulty with planning for your own or your family's fu	No.	Col %	Cum %
1 - No difficulty	196	77.8	77.8
2 - A little	32	12.7	90.5
3 - Quite a bit	7	2.8	93.3
4 - Very much	3	1.2	94.4
.a - Missing	14	5.6	100.0
Total	252	100.0	

J11 Have you had any difficulty communicating with those closest to you? - *hn3_j11_dyl_com_closest*

Table 562: 12-months - SDI - Have you had any difficulty communicating with those closest to you?

12M - Have you had any difficulty communicating with those closest to you? (e.g.	No.	Col %	Cum %
1 - No difficulty	183	72.6	72.6
2 - A little	48	19.0	91.7
3 - Quite a bit	9	3.6	95.2
4 - Very much	3	1.2	96.4
.a - Missing	9	3.6	100.0
Total	252	100.0	

J12 Have you had difficulty communicating with others? - *hn3_j12_dyl_com_others*

Table 563: 12-months - SDI - Have you had difficulty communicating with others?

12M - Have you had difficulty communicating with others? (e.g. friends, neighbou	No.	Col %	Cum %
1 - No difficulty	183	72.6	72.6
2 - A little	52	20.6	93.3
3 - Quite a bit	9	3.6	96.8
4 - Very much	2	0.8	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

J13 Have you had any difficulty concerning sexual matters? - *hn3_j13_dyl_sexual_matters*

Table 564: 12-months - SDI - Have you had any difficulty concerning sexual matters?

12M - Have you had any difficulty concerning sexual matters:	No.	Col %	Cum %
1 - No difficulty	149	59.1	59.1
2 - A little	41	16.3	75.4
3 - Quite a bit	18	7.1	82.5
4 - Very much	16	6.3	88.9
.a - Missing	28	11.1	100.0
Total	252	100.0	

J14 Have you had any difficulty concerning plans to have a family? - *hn3_j14_dyl_dif_having_fam*

Table 565: 12-months - SDI - Have you had any difficulty concerning plans to have a family?

12M - Have you had any difficulty concerning plans to have a family:	No.	Col %	Cum %
1 - No difficulty	193	76.6	76.6
2 - A little	5	2.0	78.6
3 - Quite a bit	2	0.8	79.4
4 - Very much	1	0.4	79.8
.a - Missing	51	20.2	100.0
Total	252	100.0	

J15 Have you had any difficulty concerning your appearance or body image? - *hn3_j15_dyl_body_image*

Table 566: 12-months - SDI - Have you had any difficulty concerning your appearance or body image?

12M - Have you had any difficulty concerning your appearance or body image:	No.	Col %	Cum %
1 - No difficulty	158	62.7	62.7
2 - A little	68	27.0	89.7
3 - Quite a bit	13	5.2	94.8
4 - Very much	2	0.8	95.6
.a - Missing	11	4.4	100.0
Total	252	100.0	

J16 Have you felt isolated? - *hn3_j16_dyl_felt_isolated***Table 567:** 12-months - SDI - Have you felt isolated?

12M - Have you felt isolated:	No.	Col %	Cum %
1 - No difficulty	167	66.3	66.3
2 - A little	52	20.6	86.9
3 - Quite a bit	18	7.1	94.0
4 - Very much	4	1.6	95.6
.a - Missing	11	4.4	100.0
Total	252	100.0	

J17 Have you had any difficulty with getting around? - *hn3_j17_dyl_mobility***Table 568:** 12-months - SDI - Have you had any difficulty with getting around?

12M - Have you had any difficulty with getting around? (e.g. transport, car park	No.	Col %	Cum %
1 - No difficulty	190	75.4	75.4
2 - A little	37	14.7	90.1
3 - Quite a bit	10	4.0	94.0
4 - Very much	5	2.0	96.0
.a - Missing	10	4.0	100.0
Total	252	100.0	

J18 Have you had any difficulty with where you live? - *hn3_j18_dyl_dif_live***Table 569:** 12-months - SDI - Have you had any difficulty with where you live?

12M - Have you had any difficulty with where you live? (e.g. space, access, damp	No.	Col %	Cum %
1 - No difficulty	219	86.9	86.9
2 - A little	14	5.6	92.5
3 - Quite a bit	8	3.2	95.6
4 - Very much	5	2.0	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

J19 Have you had any difficulty in carrying out your recreational activities? - *hn3_j19_dyl_dif_recreational*

Table 570: 12-months - SDI - Have you had any difficulty in carrying out your recreational activities?

12M - Have you had any difficulty in carrying out your recreational activities?	No.	Col %	Cum %
1 - No difficulty	144	57.1	57.1
2 - A little	67	26.6	83.7
3 - Quite a bit	22	8.7	92.5
4 - Very much	12	4.8	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

J20 Have you had any difficulty with your plans to travel or take a holiday? - *hn3_j20_dyl_dif_travel*

Table 571: 12-months - SDI - Have you had any difficulty with your plans to travel or take a holiday?

12M - Have you had any difficulty with your plans to travel or take a holiday:	No.	Col %	Cum %
1 - No difficulty	145	57.5	57.5
2 - A little	42	16.7	74.2
3 - Quite a bit	28	11.1	85.3
4 - Very much	23	9.1	94.4
.a - Missing	14	5.6	100.0
Total	252	100.0	

J21 Have you had any difficulty with any other area of your everyday life? - *hn3_j21_dyl_dif_other_area*

Table 572: 12-months - SDI - Have you had any difficulty with any other area of your everyday life?

12M - Have you had any difficulty with any other area of your everyday life:	No.	Col %	Cum %
1 - No difficulty	173	68.7	68.7
2 - A little	50	19.8	88.5
3 - Quite a bit	9	3.6	92.1
4 - Very much	6	2.4	94.4
.a - Missing	14	5.6	100.0
Total	252	100.0	

5.2.12 Your Appearance

The topics covered in the ‘Your Appearance’ questionnaire are based on the ‘Derriford Appearance Scale (DAS 24)’ questionnaire (Carr et al., 2005). This questionnaire was completed by participants enrolled at the Bristol centre. Further details of the questionnaire used can be found in Appendix B.4.2 on page 547.

K1A Is there any aspect of the appearance of your head/neck (however small) that concerns you at all? - *hn3_k1a_ya_appear_hn*

Table 573: 12-months - YA: [hn3 Quests Kq1a] Any aspect of the appearance of your head/neck that concerns you at all?

12M - Is there any aspect of the appearance head/neck that concerns you at all:	No.	Col %	Cum %
1 - Yes	79	31.3	31.3
2 - No	161	63.9	95.2
.a - Missing	12	4.8	100.0
Total	252	100.0	

K2A The aspect of my head/neck about which I am most sensitive or self-conscious is - *hn3_k2a_ya_aspect_hn*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K3A The thing I do not like about the appearance of my head/neck - *hn3_k3a_ya_hn_dont_like*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K4A If you are sensitive or concerned about any other features of - *hn3_k4a_ya_body_dont_like*

- This is a free text field and will not be documented. Data for this variable are available through a standard data request.

K1B How confident do you feel - *hn3_k1b_ya_confident*

Table 574: 12-months - YA: [hn3 Quests Kq1b] How confident do you feel

12M - How confident do you feel:	No.	Col %	Cum %
1 - Not at all	13	5.2	5.2
2 - Slightly	27	10.7	15.9
3 - Moderately	143	56.7	72.6
4 - Extremely	62	24.6	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

K2B How distressed do you get when you see yourself in the mirror/window: - *hn3_k2b_ya_see_yourself_mir*

Table 575: 12-months - YA: [hn3 Quests Kq2b] How distressed do you get when you see yourself in the mirror/window:

12M - How distressed do you get when you see yourself in the mirror/window:	No.	Col %	Cum %
1 - Extremely	6	2.4	2.4
2 - Moderately	27	10.7	13.1
3 - A little	60	23.8	36.9
4 - Not at all distressed	154	61.1	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

K3B My self-consciousness makes me irritable at home: - *hn3_k3b_ya_selfconscious*

Table 576: 12-months - YA: [hn3 Quests Kq3b] My self-consciousness makes me irritable at home

12M - My self-consciousness makes me irritable at home:	No.	Col %	Cum %
1 - N/A	99	39.3	39.3
2 - Never/Almost never	88	34.9	74.2
3 - Sometimes	50	19.8	94.0
4 - Often	7	2.8	96.8
5 - Almost always	1	0.4	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

K4B How hurt do you feel: - *hn3_k4b_ya_hurt_feel*

Table 577: 12-months - YA: [hn3 Quests Kq4b] How hurt do you feel

12M - How hurt do you feel:	No.	Col %	Cum %
1 - Extremely	10	4.0	4.0
2 - Moderately	33	13.1	17.1
3 - Slightly	45	17.9	34.9
4 - Not at all	159	63.1	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

K5B At present my self-consciousness has an adverse effect on my work: - *hn3_k5b_ya_selfconscious_work*

Table 578: 12-months - YA: [hn3 Quests Kq5b] At present my self-consciousness has an adverse effect on my work:

12M - At present my self-consciousness has an adverse effect on my work:	No.	Col %	Cum %
1 - Almost always	3	1.2	1.2
2 - Often	5	2.0	3.2
3 - Sometimes	17	6.7	9.9
4 - Never/almost never	55	21.8	31.7
5 - N/A	163	64.7	96.4
.a - Missing	9	3.6	100.0
Total	252	100.0	

K6B How distressed do you get when you go to the beach - *hn3_k6b_ya_distressed_beach*

Table 579: 12-months - YA: [hn3 Quests Kq6b] How distressed do you get when you go to the beach

12M - How distressed do you get when you go to the beach:	No.	Col %	Cum %
1 - N/A	139	55.2	55.2
2 - Not at all	80	31.7	86.9
3 - A little	16	6.3	93.3
4 - Moderately	5	2.0	95.2
5 - Extremely	4	1.6	96.8
.a - Missing	8	3.2	100.0
Total	252	100.0	

K7B Other people misjudge me because of the appearance of my head/neck: - *hn3_k7b_ya_misjudge*

Table 580: 12-months - YA: [hn3 Quests Kq7b] Other people misjudge me because of the appearance of my head/neck:

12M - Other people mis-judge me because of the appearance of my head/neck:	No.	Col %	Cum %
1 - Almost always	3	1.2	1.2
2 - Often	2	0.8	2.0
3 - Sometimes	18	7.1	9.1
4 - Never/almost never	96	38.1	47.2
5 - N/A	126	50.0	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

K8B How feminine/masculine do you feel - *hn3_k8b_ya_fem_masc_feel***Table 581:** 12-months - YA: [hn3 Quests Kq8b] How feminine/masculine do you feel

12M - How feminine/masculine do you feel:	No.	Col %	Cum %
1 - Not at all	24	9.5	9.5
2 - Slightly	20	7.9	17.5
3 - Moderately	93	36.9	54.4
4 - Extremely	102	40.5	94.8
.a - Missing	13	5.2	100.0
Total	252	100.0	

K19B How distressed do you get when going to social events - *hn3_k19b_ya_distressed***Table 582:** 12-months - YA: [hn3 Quests Kq19b] How distressed do you get when going to social events

12M - How distressed do you get when going to social events:	No.	Col %	Cum %
1 - N/A	72	28.6	28.6
2 - Not at all	115	45.6	74.2
3 - Moderately	49	19.4	93.7
4 - A fair amount	7	2.8	96.4
5 - Extremely	4	1.6	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

K20B How normal do you feel - *hn3_k20b_ya_normal_feel***Table 583:** 12-months - YA: [hn3 Quests Kq20b] How normal do you feel

12M - How normal do you feel:	No.	Col %	Cum %
1 - Not at all	4	1.6	1.6
2 - Slightly	23	9.1	10.7
3 - Moderately	94	37.3	48.0
4 - Extremely	123	48.8	96.8
.a - Missing	8	3.2	100.0
Total	252	100.0	

K21B At present my self-consciousness has an adverse effect on my sex life: - *hn3_k21b_ya_effect_sex_life*

Table 584: 12-months - YA: [hn3 Quests Kq21b] At present my self-consciousness has an adverse effect on my sex life:

12M - At present my self-consciousness has an adverse effect on my sex life:	No.	Col %	Cum %
1 - Almost always	17	6.7	6.7
2 - Often	13	5.2	11.9
3 - Sometimes	15	6.0	17.9
4 - Never/almost never	84	33.3	51.2
5 - N/A	108	42.9	94.0
.a - Missing	15	6.0	100.0
Total	252	100.0	

K22B Avoid going out of house - *hn3_k22b_ya_avoid_going_out*

Table 585: 12-months - YA: [hn3 Quests Kq22b] Avoid going out of house

12M - Avoid going out of house:	No.	Col %	Cum %
1 - Almost always	4	1.6	1.6
2 - Often	4	1.6	3.2
3 - Sometimes	32	12.7	15.9
4 - Never/almost never	206	81.7	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

K23B How distressed do you get when other people make remarks about the appearance of your head/neck? - *hn3_k23b_ya_remarks_hn*

Table 586: 12-months - YA: [hn3 Quests Kq23b] How distressed do you get when other people make remarks about the appearance of your head/neck?

12M - How distressed do you get when people remark about appearance of your head	No.	Col %	Cum %
1 - N/A	116	46.0	46.0
2 - Not at all	101	40.1	86.1
3 - Moderately	22	8.7	94.8
4 - A fair amount	3	1.2	96.0
5 - Extremely	4	1.6	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

K24B I avoid going to pubs/restaurants - *hn3_k24b_ya_avoid_pubs*

Table 587: 12-months - YA: [hn3 Quests Kq24b] I avoid going to pubs/restaurants

12M - I avoid going to pubs/restaurants:	No.	Col %	Cum %
1 - Almost always	13	5.2	5.2
2 - Often	5	2.0	7.1
3 - Sometimes	24	9.5	16.7
4 - Never/almost never	128	50.8	67.5
5 - N/A	78	31.0	98.4
.a - Missing	4	1.6	100.0
Total	252	100.0	

K1C My feature causes me physical pain/discomfort - *hn3_k1c_ya_features*

Table 588: 12-months - YA: [hn3 Quests Kq1c] My feature causes me physical pain/discomfort

12M - My feature causes me physical pain/discomfort:	No.	Col %	Cum %
1 - Never/almost never	176	69.8	69.8
2 - Sometimes	47	18.7	88.5
3 - Often	15	6.0	94.4
4 - Almost always	6	2.4	96.8
.a - Missing	8	3.2	100.0
Total	252	100.0	

K2C My feature limits my physical ability to do the things I want to do: - *hn3_k2c_ya_physical_ability*

Table 589: 12-months - YA: [hn3 Quests Kq2c] My feature limits my physical ability to do the things I want to do:

12M - My feature limits my physical ability to do the things I want to do:	No.	Col %	Cum %
1 - Almost always	9	3.6	3.6
2 - Often	13	5.2	8.7
3 - Sometimes	44	17.5	26.2
4 - Never/almost never	177	70.2	96.4
.a - Missing	9	3.6	100.0
Total	252	100.0	

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? - *hn3_k3c_ya_disfigurement*

Table 590: 12-months - YA: [hn3 Quests Kq3c] To what extent is any disfigurement or change to your appearance as a result of your cancer or its treatment noticeable to other people?

12M - To what extent is any disfigurement or change to your appearance as a resu	No.	Col %	Cum %
1 - Not at all noticable	102	40.5	40.5
2 - 2	63	25.0	65.5
3 - 3	25	9.9	75.4
4 - Moderately noticable	28	11.1	86.5
5 - 5	10	4.0	90.5
6 - 6	9	3.6	94.0
7 - Extremely noticable	10	4.0	98.0
.a - Missing	5	2.0	100.0
Total	252	100.0	

K4C How much will your treatment change the way you look - *hn3_k5c_ya_treatment*

Table 591: 12-months - YA: [hn3 Quests Kq5c] How much will your treatment change the way you look

12M - How much will your treatment change the way you look	No.	Col %	Cum %
1 - Not at all	92	36.5	36.5
2 - 2	82	32.5	69.0
3 - 3	37	14.7	83.7
4 - 4	17	6.7	90.5
5 - Very much	17	6.7	97.2
.a - Missing	7	2.8	100.0
Total	252	100.0	

K6C How much does this bother you - *hn3_k6c_ya_bother_you*

Table 592: 12-months - YA: [hn3 Quests Kq6c] How much does this bother you

12M - How much does this bother you	No.	Col %	Cum %
1 - Not at all	153	60.7	60.7
2 - 2	35	13.9	74.6
3 - 3	37	14.7	89.3
4 - 4	10	4.0	93.3
5 - Very much so	11	4.4	97.6
.a - Missing	6	2.4	100.0
Total	252	100.0	

5.2.13 Your Symptoms

The topics covered in the ‘Your Symptoms’ questionnaire are based on the ‘Radiotherapy Questionnaire (Late Toxicity)’ questionnaire (Ho et al., 2009). Further details of the questionnaire used can be found in Appendix B.4.4 on page 585.

L1 How severe is the pain: - *hn3_l1_ys_severe_pain*

Table 593: 12-months - YS: [HN1 Section Lq1] How severe is the pain:

12M - How severe is the pain:	No.	Col %	Cum %
1 - None	503	17.9	17.9
2 - Mild	403	14.4	32.3
3 - Moderate	171	6.1	38.4
4 - Severe	34	1.2	39.6
.a - Missing	1695	60.4	100.0
Total	2806	100.0	

L2a Where is the pain: Mouth - *hn3_l2a_ys_pain_mouth*

Table 594: 12-months - YS: [HN1 Section Lq2a] Where is the pain: Mouth

12M - Where is the pain: Mouth	No.	Col %	Cum %
1 - Yes	257	9.2	9.2
2 - No	404	14.4	23.6
.a - Missing	2145	76.4	100.0
Total	2806	100.0	

L2b Where is the pain: Throat - *hn3_l2b_ys_pain_throat*

Table 595: 12-months - YS: [HN1 Section Lq2b] Where is the pain: Throat

12M - Where is the pain: Throat	No.	Col %	Cum %
1 - Yes	283	10.1	10.1
2 - No	376	13.4	23.5
.a - Missing	2147	76.5	100.0
Total	2806	100.0	

L2c Where is the pain: Jaw - *hn3_l2c_ys_pain_jaw*

Table 596: 12-months - YS: [HN1 Section Lq2c] Where is the pain: Jaw

12M - Where is the pain: Jaw	No.	Col %	Cum %
1 - Yes	227	8.1	8.1
2 - No	434	15.5	23.6
.a - Missing	2145	76.4	100.0
Total	2806	100.0	

L2d Where is the pain: Neck - *hn3_l2d_ys_pain_neck*

Table 597: 12-months - YS: [HN1 Section Lq2d] Where is the pain: Neck

12M - Where is the pain: Neck	No.	Col %	Cum %
1 - Yes	319	11.4	11.4
2 - No	340	12.1	23.5
.a - Missing	2147	76.5	100.0
Total	2806	100.0	

L2e Where is the pain: Skin - *hn3_l2e_ys_pain_skin*

Table 598: 12-months - YS: [HN1 Section Lq2e] Where is the pain: Skin

12M - Where is the pain: Skin	No.	Col %	Cum %
1 - Yes	74	2.6	2.6
2 - No	583	20.8	23.4
.a - Missing	2149	76.6	100.0
Total	2806	100.0	

L2f Where is the pain: Ear - *hn3_l2f_ys_pain_ear*

Table 599: 12-months - YS: [HN1 Section Lq2f] Where is the pain: Ear

12M - Where is the pain: Ear	No.	Col %	Cum %
1 - Yes	133	4.7	4.7
2 - No	523	18.6	23.4
.a - Missing	2150	76.6	100.0
Total	2806	100.0	

L2g Where is the pain: Other - *hn3_l2g1_ys_pain_other*

Table 600: 12-months - YS: [HN1 Section Lq2g1] Where is the pain: Other

12M - Where is the pain: Other	No.	Col %	Cum %
1 - Yes	103	3.7	3.7
2 - No	553	19.7	23.4
.a - Missing	2150	76.6	100.0
Total	2806	100.0	

L2g Where is the pain: Please state - *hn3_l2g2_ys_pain_desc*

L3 Are you taking any medication for this pain: - *hn3_l3_ys_med_pain*

Table 601: 12-months - YS: [HN1 Section Lq3] Are you taking any medication for this pain:

12M - Are you taking any medication for this pain:	No.	Col %	Cum %
1 - No	542	19.3	19.3
2 - Yes occasionally	184	6.6	25.9
3 - Yes regularly	206	7.3	33.2
.a - Missing	1874	66.8	100.0
Total	2806	100.0	

L4a1 If Yes, please give name of medication - *hn3_l4a1_ys_med_name*

Table 602: 12-months - YS: [HN1 Section Lq4a1] If Yes, please give name of medication

L4a2 If Yes, please state how often, - *hn3_l4a2_ys_med_freq*

Table 603: 12-months - YS: [HN1 Section Lq4a2] If Yes, please state how often,

L4b1 If Yes, please give name of medication - *hn3_l4b1_ys_med_name*

Table 604: 12-months - YS: [HN1 Section Lq4b1] If Yes, please give name of medication

L4b2 If Yes, please state how often, - *hn3_l4b2_ys_med_freq*

Table 605: 12-months - YS: [HN1 Section Lq4b2] If Yes, please state how often,

L5 Does the pain or painkillers interfere with daily self care ac - *hn3_l5_ys_pain_painkillers*

Table 606: 12-months - YS: [HN1 Section Lq5] Does the pain or painkillers interfere with daily self care ac

12M - Does the pain or painkillers interfere with daily self care activities:	No.	Col %	Cum %
1 - No	732	26.1	26.1
2 - Yes	45	1.6	27.7
.a - Missing	2029	72.3	100.0
Total	2806	100.0	

L6a Have you lost your appetite: - *hn3_l6a_ys_appetite*

Table 607: 12-months - YS: [HN1 Section Lq6] Have you lost your appetite:

12M - Have you lost your appetite:	No.	Col %	Cum %
1 - No	696	24.8	24.8
2 - Yes	401	14.3	39.1
.a - Missing	1709	60.9	100.0
Total	2806	100.0	

L7 Have you had difficulties in swallowing: - *hn3_l7_ys_swallowing***Table 608:** 12-months - YS: [HN1 Section Lq7] Have you had difficulties in swallowing:

12M - Have you had difficulties in swallowing:	No.	Col %	Cum %
1 - No	476	17.0	17.0
2 - Yes	616	22.0	38.9
.a - Missing	1714	61.1	100.0
Total	2806	100.0	

L8 Have you any difficulty opening your mouth: - *hn3_l8_ys_open_mouth***Table 609:** 12-months - YS: [HN1 Section Lq8] Have you any difficulty opening your mouth:

12M - Have you any difficulty opening your mouth:	No.	Col %	Cum %
1 - No	756	26.9	26.9
2 - Yes	343	12.2	39.2
.a - Missing	1707	60.8	100.0
Total	2806	100.0	

L9 Do you have any alteration in your taste: - *hn3_l9_ys_alter_taste***Table 610:** 12-months - YS: [HN1 Section Lq9] Do you have any alteration in your taste:

12M - Do you have any alteration in your taste:	No.	Col %	Cum %
1 - No	365	13.0	13.0
2 - Yes	731	26.1	39.1
.a - Missing	1710	60.9	100.0
Total	2806	100.0	

L10 If Yes, have you had any loss of taste and I or do you find t - *hn3_l10_ys_loss_taste***Table 611:** 12-months - YS: [HN1 Section Lq10] If Yes, have you had any loss of taste and I or do you find t

12M - If Yes, have you had any loss of taste and I or do you find taste unpleasa	No.	Col %	Cum %
1 - No	320	11.4	11.4
2 - Yes	605	21.6	33.0
.a - Missing	1881	67.0	100.0
Total	2806	100.0	

L11 Have you had a dry mouth: - *hn3_l11_ys_dry_mouth*

Table 612: 12-months - YS: [HN1 Section Lq11] Have you had a dry mouth:

12M - Have you had a dry mouth:	No.	Col %	Cum %
1 - No	198	7.1	7.1
2 - Yes	899	32.0	39.1
.a - Missing	1709	60.9	100.0
Total	2806	100.0	

L12 Have you had any changes to your saliva: - *hn3_l12_ys_changes_saliva*

Table 613: 12-months - YS: [HN1 Section Lq12] Have you had any changes to your saliva:

12M - Have you had any changes to your saliva:	No.	Col %	Cum %
1 - None	311	11.1	11.1
2 - Yes its slightly thickened	444	15.8	26.9
3 - Yes its ropery thick and sticky	302	10.8	37.7
.a - Missing	1749	62.3	100.0
Total	2806	100.0	

L13 If Yes, has it affected your taste: - *hn3_l13_ys_affected_taste*

Table 614: 12-months - YS: [HN1 Section Lq13] If Yes, has it affected your taste:

12M - If Yes, has it affected your taste:	No.	Col %	Cum %
1 - No	286	10.2	10.2
2 - Yes slightly	363	12.9	23.1
3 - Yes markedly	262	9.3	32.5
.a - Missing	1895	67.5	100.0
Total	2806	100.0	

L14 If you have saliva changes, how has it affected your daily se - *hn3_l14_ys_saliva_changes*

Table 615: 12-months - YS: [HN1 Section Lq14] If you have saliva changes, how has it affected your daily se

12M - If you have saliva changes, how has it affected your daily self care activ	No.	Col %	Cum %
1 - Not at all	887	31.6	31.6
2 - Interferes with self care activities	89	3.2	34.8
3 - Unable to self care	3	0.1	34.9
.a - Missing	1827	65.1	100.0
Total	2806	100.0	

L15 Has your diet been significantly affected: - *hn3_l15_ys_diet_affected*

Table 616: 12-months - YS: [HN1 Section Lq15] Has your diet been significantly affected:

12M - Has your diet been significantly affected:	No.	Col %	Cum %
1 - Normal regular diet	427	15.2	15.2
2 - Yes but can manage solid food	353	12.6	27.8
3 - Yes mostly soft or liquidised food	241	8.6	36.4
4 - Cannot eat I swallow adequately or need fluid drip I tube feeding	69	2.5	38.8
.a - Missing	1716	61.2	100.0
Total	2806	100.0	

L16a If your diet has been significantly affected, what has cause - *hn3_l16a_ys_diet_swallowing*

Table 617: 12-months - YS: [HN1 Section Lq16a] If your diet has been significantly affected, what has cause

12M - If your diet has been significantly affected, what has caused it: Difficul	No.	Col %	Cum %
1 - No	289	10.3	10.3
2 - Yes	445	15.9	26.2
.a - Missing	2072	73.8	100.0
Total	2806	100.0	

L16b If your diet has been significantly affected, what has cause - *hn3_l16b_ys_diet_dry*

Table 618: 12-months - YS: [HN1 Section Lq16b] If your diet has been significantly affected, what has cause

12M - If your diet has been significantly affected, what has caused it: Dry mout	No.	Col %	Cum %
1 - No	230	8.2	8.2
2 - Yes	505	18.0	26.2
.a - Missing	2071	73.8	100.0
Total	2806	100.0	

L16c If your diet has been significantly affected, what has cause - *hn3_l16c_ys_diet_opening*

Table 619: 12-months - YS: [HN1 Section Lq16c] If your diet has been significantly affected, what has cause

12M - If your diet has been significantly affected, what has caused it: Difficul	No.	Col %	Cum %
1 - No	570	20.3	20.3
2 - Yes	156	5.6	25.9
.a - Missing	2080	74.1	100.0
Total	2806	100.0	

L16d If your diet has been significantly affected, what has cause - *hn3_l16d_ys_diet_appetite*

Table 620: 12-months - YS: [HN1 Section Lq16d] If your diet has been significantly affected, what has cause

12M - If your diet has been significantly affected, what has caused it: Loss of	No.	Col %	Cum %
1 - No	459	16.4	16.4
2 - Yes	270	9.6	26.0
.a - Missing	2077	74.0	100.0
Total	2806	100.0	

L16e If your diet has been significantly affected, what has cause - *hn3_l16e_ys_diet_taste*

Table 621: 12-months - YS: [HN1 Section Lq16e] If your diet has been significantly affected, what has cause

12M - If your diet has been significantly affected, what has caused it: Altered	No.	Col %	Cum %
1 - No	370	13.2	13.2
2 - Yes	362	12.9	26.1
.a - Missing	2074	73.9	100.0
Total	2806	100.0	

L16f If your diet has been significantly affected, what has cause - *hn3_l16f_ys_diet_saliva*

Table 622: 12-months - YS: [HN1 Section Lq16f] If your diet has been significantly affected, what has cause

12M - If your diet has been significantly affected, what has caused it: Change i	No.	Col %	Cum %
1 - No	384	13.7	13.7
2 - Yes	345	12.3	26.0
.a - Missing	2077	74.0	100.0
Total	2806	100.0	

L16g1 If your diet has been significantly affected, what has caus - *hn3_l16g1_ys_diet_others*

Table 623: 12-months - YS: [HN1 Section Lq16g1] If your diet has been significantly affected, what has caus

12M - If your diet has been significantly affected, what has caused it: Others	No.	Col %	Cum %
1 - No	641	22.8	22.8
2 - Yes	81	2.9	25.7
.a - Missing	2084	74.3	100.0
Total	2806	100.0	

L17a If you are on supplementary nutritional drinks, why are you - *hn3_l17a_ys_drinks_not_on*

Table 624: 12-months - YS: [HN1 Section Lq17a] If you are on supplementary nutritional drinks, why are you

12M - If you are on supplementary nutritional drinks, why are you requiring them	No.	Col %	Cum %
1 - No	240	8.6	8.6
2 - Yes	638	22.7	31.3
.a - Missing	1928	68.7	100.0
Total	2806	100.0	

L17b If you are on supplementary nutritional drinks, why are you - *hn3_l17b_ys_drinks_swallow*

Table 625: 12-months - YS: [HN1 Section Lq17b] If you are on supplementary nutritional drinks, why are you

12M - If you are on supplementary nutritional drinks, why are you requiring them	No.	Col %	Cum %
1 - No	706	25.2	25.2
2 - Yes	157	5.6	30.8
.a - Missing	1943	69.2	100.0
Total	2806	100.0	

L17c If you are on supplementary nutritional drinks, why are you - *hn3_l17c_ys_drinks_weight*

Table 626: 12-months - YS: [HN1 Section Lq17c] If you are on supplementary nutritional drinks, why are you

12M - If you are on supplementary nutritional drinks, why are you requiring them	No.	Col %	Cum %
1 - No	638	22.7	22.7
2 - Yes	225	8.0	30.8
.a - Missing	1943	69.2	100.0
Total	2806	100.0	

L17d If you are on supplementary nutritional drinks, why are you - *hn3_l17d_ys_drinks_appetite*

Table 627: 12-months - YS: [HN1 Section Lq17d] If you are on supplementary nutritional drinks, why are you

12M - If you are on supplementary nutritional drinks, why are you requiring them	No.	Col %	Cum %
1 - No	722	25.7	25.7
2 - Yes	142	5.1	30.8
.a - Missing	1942	69.2	100.0
Total	2806	100.0	

L17e If you are on supplementary nutritional drinks, why are you - *hn3_l17e_ys_drinks_taste*

Table 628: 12-months - YS: [HN1 Section Lq17e] If you are on supplementary nutritional drinks, why are you

12M - If you are on supplementary nutritional drinks, why are you requiring them	No.	Col %	Cum %
1 - No	769	27.4	27.4
2 - Yes	93	3.3	30.7
.a - Missing	1944	69.3	100.0
Total	2806	100.0	

L17f1 If you are on supplementary nutritional drinks, why are you - *hn3_l17f1_ys_drinks_others*

Table 629: 12-months - YS: [HN1 Section Lq17f1] If you are on supplementary nutritional drinks, why are you

12M - If you are on supplementary nutritional drinks, why are you requiring them	No.	Col %	Cum %
1 - No	817	29.1	29.1
2 - Yes	42	1.5	30.6
.a - Missing	1947	69.4	100.0
Total	2806	100.0	

L18 Have you any visible roughness or flaking of your skin: - *hn3_l18_ys_flaking_skin*

Table 630: 12-months - YS: [HN1 Section Lq18] Have you any visible roughness or flaking of your skin:

12M - Have you any visible roughness or flaking of your skin:	No.	Col %	Cum %
1 - No	813	29.0	29.0
2 - Yes	267	9.5	38.5
.a - Missing	1726	61.5	100.0
Total	2806	100.0	

L19 If Yes, how obvious is it: - *hn3_l19_ys_how_obvious*

Table 631: 12-months - YS: [HN1 Section Lq19] If Yes, how obvious is it:

12M - If Yes, how obvious is it:	No.	Col %	Cum %
1 - Only close-up	209	7.4	7.4
2 - Easily apparent	92	3.3	10.7
.a - Missing	2505	89.3	100.0
Total	2806	100.0	

L20 If Yes, does this affect your appearance: - *hn3_l20_ys_appearance*

Table 632: 12-months - YS: [HN1 Section Lq20] If Yes, does this affect your appearance:

12M - If Yes, does this affect your appearance:	No.	Col %	Cum %
1 - No	257	9.2	9.2
2 - Yes	100	3.6	12.7
3 - Would like surgery if feasible	9	0.3	13.0
.a - Missing	2440	87.0	100.0
Total	2806	100.0	

L21 Have you any thickening or hardening of your skin (skin fibro - *hn3_l21_ys_thick_skin*

Table 633: 12-months - YS: [HN1 Section Lq21] Have you any thickening or hardening of your skin (skin fibro

12M - Have you any thickening or hardening of your skin (skin fibrosis):	No.	Col %	Cum %
1 - No	755	26.9	26.9
2 - Yes	201	7.2	34.1
.a - Missing	1850	65.9	100.0
Total	2806	100.0	

L22 If Yes, how severe is the skin thickening / hardening: - *hn3_l22_ys_sev_skin_thick*

Table 634: 12-months - YS: [HN1 Section Lq22] If Yes, how severe is the skin thickening / hardening:

12M - If Yes, how severe is the skin thickening / hardening:	No.	Col %	Cum %
1 - Mild	165	5.9	5.9
2 - Marked	66	2.4	8.2
3 - interferes with self care activities	9	0.3	8.6
.a - Missing	2566	91.4	100.0
Total	2806	100.0	

L23 Have you any skin itchiness: - *hn3_l23_ys_skin_itchiness*

Table 635: 12-months - YS: [HN1 Section Lq23] Have you any skin itchiness:

12M - Have you any skin itchiness:	No.	Col %	Cum %
1 - No	686	24.4	24.4
2 - Mild and localised	295	10.5	35.0
3 - Intense or widespread	15	0.5	35.5
4 - Interferes with self care activities	4	0.1	35.6
.a - Missing	1806	64.4	100.0
Total	2806	100.0	

L24 Do you have any puffiness in your head and neck: - *hn3_l24_ys_puffiness*

Table 636: 12-months - YS: [HN1 Section Lq24] Do you have any puffiness in your head and neck:

12M - Do you have any puffiness in your head and neck:	No.	Col %	Cum %
1 - No	606	21.6	21.6
2 - Yes	439	15.6	37.2
.a - Missing	1761	62.8	100.0
Total	2806	100.0	

L25 If Yes, has it interfered with any function (eg turning your - *hn3_l25_ys_function*

Table 637: 12-months - YS: [HN1 Section Lq25] If Yes, has it interfered with any function (eg turning your

12M - If Yes, has it interfered with any function (eg turning your head or openi	No.	Col %	Cum %
1 - No	417	14.9	14.9
2 - Yes	241	8.6	23.4
.a - Missing	2148	76.6	100.0
Total	2806	100.0	

L26 Are you getting any hoarseness/voice changes - *hn3_l26_ys_hoarse_voice*

Table 638: 12-months - YS: [HN1 Section Lq26] Are you getting any hoarseness/voice changes

12M - Are you getting any hoarseness/voice changes	No.	Col %	Cum %
1 - None	414	14.8	14.8
2 - Yes intermittently	473	16.9	31.6
3 - Yes persistently	164	5.8	37.5
4 - Voice box has been removed(laryngectomy)	33	1.2	38.6
.a - Missing	1722	61.4	100.0
Total	2806	100.0	

L27 If you have hoarseness / voice change, how severe is it: - *hn3_l27_ys_voice_change*

Table 639: 12-months - YS: [HN1 Section Lq27] If you have hoarseness / voice change, how severe is it:

12M - If you have hoarseness / voice change, how severe is it:	No.	Col %	Cum %
1 - Mild	401	14.3	14.3
2 - Moderate	225	8.0	22.3
3 - Severe and predominantly whispered speech	38	1.4	23.7
4 - Complete loss of voice	15	0.5	24.2
.a - Missing	2127	75.8	100.0
Total	2806	100.0	

L28 Can voice be understood: - *hn3_l28_ys_voice_understood*

Table 640: 12-months - YS: [HN1 Section Lq28] Can voice be understood:

12M - Can voice be understood:	No.	Col %	Cum %
1 - Fully understandable	668	23.8	23.8
2 - Needs occasional repetition but understandable on phone	294	10.5	34.3
3 - Needs frequent repetition or face to face contact to understand	74	2.6	36.9
4 - Non-understandable requires voice aid machine or writing	12	0.4	37.3
.a - Missing	1758	62.7	100.0
Total	2806	100.0	

L29 Have you had any hearing loss: - *hn3_l29_ys_hearing_loss*

Table 641: 12-months - YS: [HN1 Section Lq29] Have you had any hearing loss:

12M - Have you had any hearing loss:	No.	Col %	Cum %
1 - No	717	25.6	25.6
2 - Yes	360	12.8	38.4
.a - Missing	1729	61.6	100.0
Total	2806	100.0	

L30 If Yes, how severe has this been: - *hn3_l30_ys_hearing_severity*

Table 642: 12-months - YS: [HN1 Section Lq30] If Yes, how severe has this been:

12M - If Yes, how severe has this been:	No.	Col %	Cum %
1 - Minor	153	5.5	5.5
2 - Frequent difficulty with faint speech	170	6.1	11.5
3 - Frequent difficulty with loud speech	44	1.6	13.1
4 - Complete deafness	9	0.3	13.4
.a - Missing	2430	86.6	100.0
Total	2806	100.0	

L31 Do you require a hearing aid: - *hn3_l31_ys_hearing_aid*

Table 643: 12-months - YS: [HN1 Section Lq31] Do you require a hearing aid:

12M - Do you require a hearing aid:	No.	Col %	Cum %
1 - No	771	27.5	27.5
2 - Yes	145	5.2	32.6
.a - Missing	1890	67.4	100.0
Total	2806	100.0	

L32 Are you getting any noise or ringing in your ears: - *hn3_l32_ys_hearing_noises*

Table 644: 12-months - YS: [HN1 Section Lq32] Are you getting any noise or ringing in your ears:

12M - Are you getting any noise or ringing in your ears:	No.	Col %	Cum %
1 - No	620	22.1	22.1
2 - Yes rarely	144	5.1	27.2
3 - Yes sometimes	160	5.7	32.9
4 - Yes often	172	6.1	39.1
.a - Missing	1710	60.9	100.0
Total	2806	100.0	

L33 If Yes, how has it affected your daily self care activities: - *hn3_l33_ys_hearing_selfcare*

Table 645: 12-months - YS: [HN1 Section Lq33] If Yes, how has it affected your daily self care activities:

12M - If Yes, how has it affected your daily self care activities:	No.	Col %	Cum %
1 - Not at all	587	20.9	20.9
2 - interferes with self care activities	36	1.3	22.2
3 - Cannot self care	3	0.1	22.3
.a - Missing	2180	77.7	100.0
Total	2806	100.0	

Appendix A Modified Scoring Protocols

A.1 Simplified TNM Staging

Simplified grouping of TNM Staging

Larynx, Oropharynx, Hypopharynx, Oral Cavity, Salivary Glands, and Paranasal Sinuses

Assumptions:

- T2, T2a and T2b are equivalent
- T4, T4a and T4b are equivalent
- M0, Mx and M. are equivalent

Stage Grouping	T stage	N stage	M stage	Summarised
Stage I	T1	N0	(M0 OR M.)	T1 & N0 & (M0 OR M.)
Stage II	T2	N0	(M0 OR M.)	T2 & N0 & (M0 OR M.)
Stage III	T3	N0	(M0 OR M.)	(T3 & N0 & (M0 OR M.)) or (T1-3 & N1 & (M0 OR M.))
	T1-3	N1	(M0 OR M.)	
Stage IV	T1-3 T4	N2	M1	(T1-3 & N2) or T4 or N3 or M1
		N3		

Note – M. = M code missing

Nasopharynx

Assumptions:

- T1, T1a and T1b are equivalent
- T2, T2a and T2b are equivalent
- T4, T4a and T4b are equivalent
- M0, Mx and M. are equivalent

Stage Grouping	T stage	N stage	M stage	Summarised
Stage I	T1	N0	(M0 OR M.)	T1 & N0 & (M0 OR M.)
Stage II	T2	N0	(M0 OR M.)	(T2 & N0 & (M0 OR M.)) or (T1-2 & N1 & (M0 OR M.))
	T1-2	N1	(M0 OR M.)	
Stage III	T1-3	N2	(M0 OR M.)	(T1-3 & N2 & (M0 OR M.)) or (T3 & N0-1 & (M0 OR M.))
	T3	N0-1	(M0 OR M.)	
Stage IV	T4	N3	M1	T4 or N3 or M1

Note – M. = M code missing

Thyroid

Assumptions:

- T1, T1a and T1b are equivalent
- T2, T2a and T2b are equivalent
- T4, T4a and T4b are equivalent
- N1 and N1a are equivalent
- N1b and N2 are equivalent
- M0, Mx and M. are equivalent

SNOMED codes:

- Papillary and follicular
 - 8050/3, 8070/3, 8071/3, 8140/3, 8160/3, 8330/3, 8331/3, 8340/3, 8341/3, 8345/3, 8452/3
- Medullary carcinoma
 - 8452/1, 8510/3
- Anaplastic carcinoma
 - 8021/3, 8021/6, 8021/9

Papillary and Follicular (younger than 45 years)

Stage Grouping	T stage	N stage	M stage
Stage I			(M0 OR M.)
Stage II			M1

Papillary or Follicular (45 years and older) or Medullary Carcinoma

Stage Grouping	T stage	N stage	M stage	Summarised
Stage I	T1	N0	(M0 OR M.)	T1 & N0 & (M0 OR M.)
Stage II	T2	N0	(M0 OR M.)	T2 & N0 & (M0 OR M.)
Stage III	T3	N0	(M0 OR M.)	(T3 & N0 & (M0 OR M.)) or (T1-3 & N1-1a & (M0 OR M.))
	T1-3	N1-1a	(M0 OR M.)	
Stage IV	T1-3	N1b-2	(M0 OR M.)	(T1-3 & N1b & (M0 OR M.)) or T4 or N3 or M1
	T4	N3	M1	

Anaplastic Carcinoma

Stage Grouping	T stage	N stage	M stage	Summarised
Stage IV	T4		(M0 OR M.) M1	(T4 & (M0 OR M.)) or M1

Appendix B Study Documents

B.1 Baseline

B.1.1 Data Capture Form

Study ID number Participant Initials **BASELINE**headandneck
5000

A – BASIC DATA					
A1. DATE OF CONSENT (day/month/year)			A2. DATE OF BIRTH (day/month/year)		
<input type="text"/>			<input type="text"/>		
A3. DATE OF REFERRAL			A4. DIAGNOSIS DATE (date of first definitive pathology report)		
<input type="text"/>			<input type="text"/>		
A5. PRIMARY DIAGNOSIS (ICD code)		<input type="text"/>		Or describe:	
A6. HISTOLOGY (SNOMED)		<input type="text"/>		Or describe:	
A7. MDT TREATMENT DECISION DATE		<input type="text"/>			
A8. SEX	A. Female <input type="checkbox"/>	B. Male <input type="checkbox"/>	A9. ETHNICITY		<input type="text"/>
B1. CANCER PLAN INTENT					
A. Curative <input type="checkbox"/>		B. Palliative anti-cancer <input type="checkbox"/>		C. Supportive <input type="checkbox"/>	D. No specific anti-cancer <input type="checkbox"/>
B2. PLANNED CANCER TREATMENT TYPE (Please, tick all that apply)					
A. Surgery (primary site) <input type="checkbox"/>		B. Surgery (neck) <input type="checkbox"/>			
C. Teletherapy (Radiotherapy) <input type="checkbox"/>		D. Chemotherapy <input type="checkbox"/>			
E. Hormone therapy <input type="checkbox"/>		F. Specialist palliative <input type="checkbox"/>			
G. Brachytherapy <input type="checkbox"/>		H. Biological <input type="checkbox"/>			
I. Other <input type="checkbox"/>		J. Active monitoring <input type="checkbox"/>			
K. Combined chemoradiotherapy <input type="checkbox"/>		L. Reconstruction with free flap <input type="checkbox"/>			
B3. TREATMENT TYPE SEQUENCE	1. <input type="text"/>	2. <input type="text"/>	3. <input type="text"/>	4. <input type="text"/>	5. <input type="text"/>
B4. CO-MORBIDITY INDEX					
A. No co-morbidity <input type="checkbox"/>		B. Mild decompensation <input type="checkbox"/>		C. Moderate decompensation <input type="checkbox"/>	
D. Severe decompensation <input type="checkbox"/>		E. Unknown <input type="checkbox"/>			
B5. TNM CATEGORY (final pre-treatment staging)		B. T <input type="text"/>		C. N <input type="text"/>	D. M <input type="text"/>
Bilateral field to be added to database		A. Left <input type="checkbox"/>	B. Right <input type="checkbox"/>	C. Midline <input type="checkbox"/>	D. N/A <input type="checkbox"/>
B6. Side of primary tumour	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
B7. Side of neck disease	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
B8. IS THIS TUMOUR?	A. First primary <input type="checkbox"/>				
B9A. p16 HPV STATUS	1. Positive <input type="checkbox"/>	2. Negative <input type="checkbox"/>	3. Not obtained <input type="checkbox"/>		
B9B. HPV DNA by ISH	1. Positive <input type="checkbox"/>	2. Negative <input type="checkbox"/>	3. Not obtained <input type="checkbox"/>		
B9C. HPV DNA by PCR	1. Positive <input type="checkbox"/>	2. Negative <input type="checkbox"/>	3. Not obtained <input type="checkbox"/>		
C – OTHER					
C1. PATIENT TRIAL STATUS (for other trials)		A. Eligible and entered <input type="checkbox"/>		B. Eligible, declined <input type="checkbox"/>	
C. Eligible, not approached <input type="checkbox"/>		D. Ineligible <input type="checkbox"/>		E. Not applicable <input type="checkbox"/>	
C2. COMMENTS: _____					

PRIMARY DIAGNOSIS ICD CODE**Oral Cavity**

C00.3 Lip, inner aspect, mucosa of upper
 C00.4 Lip, inner aspect, mucosa of lower
 C06.0 Cheek mucosa
 C06.1 Mouth, vestibule (buccal sulcus and labial)
 C06.2 Retromolar trigone
 C03.0 Gum, upper (alveolar ridge, mucosa, gingiva)
 C03.1 Gum, lower (alveolar ridge, mucosa, gingiva)
 C04.0 Mouth, anterior floor
 C04.1 Mouth, lateral floor
 C04.8 Mouth, floor, overlapping lesion
 C.05.0 Palate, hard
 C.02.0 Tongue, dorsal surface, anterior 2/3
 C02.1 Tongue, lateral border, tip of tongue
 C02.2 Tongue, ventral, inferior surface
 C.02.8 Tongue, overlapping lesion of anterior two-third
 C02.3 Anterior two-thirds of tongue, part unspecified
 C06.8 Overlapping lesion of other and unspecified parts of mouth
 C02.4 Lingual tonsil (previously in oropharynx)

Oropharynx

C09.0 Tonsillar fossa
 C09.1 Tonsillar pillar, glossotonsillar sulcus
 C09.9 Tonsil, not otherwise specified
 C10.2 Lateral wall oropharynx
 C01 Base of tongue
 C10.0 Vallecula (Anterior surface epiglottis – see supraglottic larynx)
 C10.3 Posterior wall oropharynx
 C05.1 Palate, soft, inferior surface
 C05.2 Uvula
 C05.8 Overlapping lesion palate
 C10.8 Overlapping lesion of oropharynx
 C10.9 Oropharynx unspecified

Nasopharynx

C11.0 Nasopharynx, roof
 C11.1 Nasopharynx, posterior wall
 C11.2 Nasopharynx, lateral wall, fossa of Rosenmuller
 C11.3 Nasopharynx, inferior, upper surface soft palate
 C11.8 Nasopharynx, overlapping lesion
 C11.9 Nasopharynx unspecified

Hypopharynx

C12.x or C12.9 Pyriform sinus
 C13.0 Postcricoid region
 C13.1 Aryepiglottic fold, hypopharyngeal aspect
 C13.2 Hypopharynx, posterior wall
 C13.8 Hypopharynx, overlapping lesion
 C13.9 Hypopharynx unspecified

Larynx

Supraglottis – subsite OPTIONAL BAHNO

SUPPLEMENTARY CODES

C32.1 Supraglottis
 C10.1 Anterior surface epiglottis
 C32.1A Suprahoid epiglottis (tip, laryngeal surface)
 C32.1B Aryepiglottic fold, laryngeal aspect

C32.3A Arytenoid
 C32.1D Infrahyoid epiglottis
 C32.1E False cords

**Glottis – subsite

OPTIONAL BAHNO SUPPLEMENTARY CODES

C32.0 Glottis
 C32.0B Anterior commissure
 C32.0C Posterior commissure
 C32.9 Larynx, not otherwise specified
 C32.0A Vocal cords, true Subglottis
 C32.2 Subglottis
 C32.3 Laryngeal cartilage
 C32.3B Cricoid cartilage
 C32.3C Thyroid cartilage

Thyroid

C73 Thyroid

Lymphomas

C81-C96 Malignant neoplasms of lymphoid, haematopoietic and related tissue

Major Salivary Glands (for minor refer to anatomic site found)

C07.x or C07.9 Parotid gland
 C08.0 Submandibular, submaxillary gland
 C08.1 Sublingual gland

HISTOLOGY (SNOMED)**Squamous carcinoma and variants**

M8075/3 Adenoid squamous carcinoma
 M8560/3 Adenosquamous carcinoma
 M8071/3 Keratinising squamous carcinoma
 M8072/3 Non-keratinising squamous carcinoma
 M8074/3 Spindle cell squamous carcinoma
 M8070/3 Squamous carcinoma (Not Otherwise Specified)
 M8051/3 Verrucous carcinoma
Salivary malignancies
 M8550/3 Acinic cell carcinoma
 M8140/3 Adenocarcinoma
 M8200/3 Adenoid cystic carcinoma
 M8147/3 Basal cell adenocarcinoma
 M8941/3 Carcinoma in pleomorphic adenoma (malignant mixed tumour)
 M8562/3 Epithelial-myoepithelial carcinoma
 M8480/3 Mucinous adenocarcinoma
 M8430/3 Mucoepidermoid carcinoma
 M8525/3 Polymorphous low grade adenocarcinoma (terminal duct adenocarcinoma)
 M8500/3 Salivary duct carcinoma
 M8041/3 Small cell carcinoma
 M8070/3 Squamous carcinoma (Not Otherwise Specified)
 M8020/3 Undifferentiated carcinoma

Ethnic Categories

A1 - White -British
B1 - White -Irish
C1 - Any other White background
D1 - Mixed -White and Black Caribbean
E1 - Mixed -White and Black African
F1 - Mixed -White and Asian
G1 - Any other Mixed background
H1 - Asian -Indian or British Indian
J1 - Asian -Pakistani or British Pakistani
K1 - Asian -Bangladeshi or British Bangladeshi
L1 - Any other Asian background
M1 - Black -Caribbean or British Caribbean
N1 - Black -African or British African
P1 - Any other Black background
R1 - Chinese
S1 - Any other Ethnic group
Z1 - Not stated/given
Z2 - Patient Refused

Adult Comorbidity Evaluation-27

Identify the important medical comorbidities and grade severity using the index.

Overall Comorbidity Score is defined according to the highest ranked single ailment, except in the case where two or more Grade 2 ailments occur in different organ systems. In this situation, the overall comorbidity score should be designated Grade 3.

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Cardiovascular system			
Myocardial Infarct	<input type="checkbox"/> MI ≤ 6 months	<input type="checkbox"/> MI > 6 months ago	<input type="checkbox"/> MI by ECG only, age undetermined
Angina / Coronary Artery Disease	<input type="checkbox"/> Unstable angina	<input type="checkbox"/> Chronic exertional angina <input type="checkbox"/> Recent (≤ 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty(PTCA) <input type="checkbox"/> Recent (≤ 6 months) coronary stent	<input type="checkbox"/> ECG or stress test evidence or catheterization evidence of coronary disease without symptoms <input type="checkbox"/> Angina pectoris not requiring hospitalization <input type="checkbox"/> CABG or PTCA (>6 mos.) <input type="checkbox"/> Coronary stent (>6 mos.)
Congestive Heart Failure (CHF)	<input type="checkbox"/> Hospitalized for CHF within past 6 months <input type="checkbox"/> Ejection fraction < 20%	<input type="checkbox"/> Hospitalized for CHF >6 months prior <input type="checkbox"/> CHF with dyspnea which limits activities	<input type="checkbox"/> CHF with dyspnea which has responded to treatment <input type="checkbox"/> Exertional dyspnea <input type="checkbox"/> Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	<input type="checkbox"/> Ventricular arrhythmia ≤ 6 months	<input type="checkbox"/> Ventricular arrhythmia > 6 months <input type="checkbox"/> Chronic atrial fibrillation or flutter <input type="checkbox"/> Pacemaker	<input type="checkbox"/> Sick Sinus Syndrome <input type="checkbox"/> Supraventricular tachycardia
Hypertension	<input type="checkbox"/> DBP>130 mm Hg <input type="checkbox"/> Severe malignant papilledema or other eye changes <input type="checkbox"/> Encephalopathy	<input type="checkbox"/> DBP 115-129 mm Hg <input type="checkbox"/> DBP 90-114 mm Hg while taking antihypertensive medications <input type="checkbox"/> Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	<input type="checkbox"/> DBP 90-114 mm Hg while not taking antihypertensive medications <input type="checkbox"/> DBP <90 mm Hg while taking antihypertensive medications <input type="checkbox"/> Hypertension, not otherwise specified
Venous Disease	<input type="checkbox"/> Recent PE (≤ 6 mos.) <input type="checkbox"/> Use of venous filter for PE's	<input type="checkbox"/> DVT controlled with Coumadin or heparin <input type="checkbox"/> Old PE > 6 months	<input type="checkbox"/> Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency < 6 months ago <input type="checkbox"/> Untreated thoracic or abdominal aneurysm (>6 cm)	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency > 6 months ago <input type="checkbox"/> Chronic insufficiency	<input type="checkbox"/> Intermittent claudication <input type="checkbox"/> Untreated thoracic or abdominal aneurysm (< 6 cm) <input type="checkbox"/> s/p abdominal or thoracic aortic aneurysm repair
Respiratory System			
	<input type="checkbox"/> Marked pulmonary insufficiency <input type="checkbox"/> Restrictive Lung Disease or COPD with dyspnea at rest despite treatment <input type="checkbox"/> Chronic supplemental O2 <input type="checkbox"/> CO2 retention (pCO2 > 50 torr) <input type="checkbox"/> Baseline pO2 < 50 torr <input type="checkbox"/> FEV1 (< 50%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities <input type="checkbox"/> FEV1 (51%-65%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment <input type="checkbox"/> FEV1 (66%-80%)
Gastrointestinal System			
Hepatic	<input type="checkbox"/> Portal hypertension and/or esophageal bleeding ≤ 6 mos. (Encephalopathy, Ascites, Jaundice with Total Bilirubin > 2)	<input type="checkbox"/> Chronic hepatitis, cirrhosis, portal hypertension with moderate symptoms "compensated hepatic failure"	<input type="checkbox"/> Chronic hepatitis or cirrhosis without portal hypertension <input type="checkbox"/> Acute hepatitis without cirrhosis <input type="checkbox"/> Chronic liver disease manifested on biopsy or persistently elevated bilirubin (>3 mg/dl)
Stomach / Intestine	<input type="checkbox"/> Recent ulcers(≤ 6 months ago) requiring blood transfusion	<input type="checkbox"/> Ulcers requiring surgery or transfusion > 6 months ago	<input type="checkbox"/> Diagnosis of ulcers treated with meds <input type="checkbox"/> Chronic malabsorption syndrome <input type="checkbox"/> Inflammatory bowel disease (IBD) on meds or h/o with complications and/or surgery
Pancreas	<input type="checkbox"/> Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	<input type="checkbox"/> Uncomplicated acute pancreatitis <input type="checkbox"/> Chronic pancreatitis with minor complications (malabsorption, impaired glucose tolerance, or GI bleeding)	<input type="checkbox"/> Chronic pancreatitis w/o complications

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Renal System			
End-stage renal disease	<input type="checkbox"/> Creatinine > 3 mg% with multi-organ failure, shock, or sepsis <input type="checkbox"/> Acute dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine >3 mg% <input type="checkbox"/> Chronic dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine 2-3 mg%.
Endocrine System (Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)			
Diabetes Mellitus	<input type="checkbox"/> Hospitalization ≤ 6 months for DKA <input type="checkbox"/> Diabetes causing end-organ failure <input type="checkbox"/> retinopathy <input type="checkbox"/> neuropathy <input type="checkbox"/> nephropathy* <input type="checkbox"/> coronary disease* <input type="checkbox"/> peripheral arterial disease*	<input type="checkbox"/> IDDM without complications <input type="checkbox"/> Poorly controlled AODM with oral agents	<input type="checkbox"/> AODM controlled by oral agents only
Neurological System			
Stroke	<input type="checkbox"/> Acute stroke with significant neurologic deficit	<input type="checkbox"/> Old stroke with neurologic residual	<input type="checkbox"/> Stroke with no residual <input type="checkbox"/> Past or recent TIA
Dementia	<input type="checkbox"/> Severe dementia requiring full support for activities of daily living	<input type="checkbox"/> Moderate dementia (not completely self-sufficient, needs supervising)	<input type="checkbox"/> Mild dementia (can take care of self)
Paralysis	<input type="checkbox"/> Paraplegia or hemiplegia requiring full support for activities of daily living	<input type="checkbox"/> Paraplegia or hemiplegia requiring wheelchair, able to do some self care	<input type="checkbox"/> Paraplegia or hemiplegia, ambulatory and providing most of self care
Neuromuscular	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care
Psychiatric			
	<input type="checkbox"/> Recent suicidal attempt <input type="checkbox"/> Active schizophrenia	<input type="checkbox"/> Depression or bipolar disorder uncontrolled <input type="checkbox"/> Schizophrenia controlled w/ meds	<input type="checkbox"/> Depression or bipolar disorder controlled w/ medication
Rheumatologic (Incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)			
	<input type="checkbox"/> Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)	<input type="checkbox"/> Connective Tissue Disorder on steroids or immunosuppressant medications	<input type="checkbox"/> Connective Tissue Disorder on NSAIDS or no treatment
Immunological System (AIDS should not be considered a comorbidity for Kaposi's Sarcoma or Non-Hodgkin's Lymphoma)			
AIDS	<input type="checkbox"/> Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)	<input type="checkbox"/> HIV+ with h/o defining illness. CD4+ < 200/μL	<input type="checkbox"/> Asymptomatic HIV+ patient. <input type="checkbox"/> HIV+ w/o h/o AIDS defining illness. CD4+ > 200/μL
Malignancy (Excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)			
Solid Tumor including melanoma	<input type="checkbox"/> Uncontrolled cancer <input type="checkbox"/> Newly diagnosed but not yet treated <input type="checkbox"/> Metastatic solid tumor	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated within the last 5 years	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated > 5 years ago
Leukemia and Myeloma	<input type="checkbox"/> Relapse <input type="checkbox"/> Disease out of control	<input type="checkbox"/> 1st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o leukemia or myeloma with last Rx > 1 yr prior
Lymphoma	<input type="checkbox"/> Relapse	<input type="checkbox"/> 1st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o lymphoma w/ last Rx >1 yr prior
Substance Abuse (Must be accompanied by social, behavioral, or medical complications)			
Alcohol	<input type="checkbox"/> Delirium tremens	<input type="checkbox"/> Active alcohol abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o alcohol abuse but not presently drinking
Illicit Drugs	<input type="checkbox"/> Acute Withdrawal Syndrome	<input type="checkbox"/> Active substance abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o substance abuse but not presently using
Body Weight			
Obesity		<input type="checkbox"/> Morbid (i.e., BMI ≥ 38)	

OVERALL COMORBIDITY SCORE (circle one.) **0** **1** **2** **3** **9**

None Mild Moderate Severe Unknown

Rev November 2003

Washington University School of Medicine

Clinical Outcomes Research Office

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B.2 Baseline Questionnaires

B.2.1 About You Questionnaire

Study ID: __ __ / __ __ __ __

Patient Initials: _____



Questionnaire “About You” – Baseline

Version 3.1**19 July 2010**

Study ID: __ / __ / __

Patient Initials: _____

About YouA1. Date (day/month/year) / / A2. What is your date of birth? (day/month/year) / / A3. How tall are you without shoes? cm OR feet inchA4. What is your current weight? Kg OR Stone lbs

A5. Are you currently?

Single ☐Widowed ☐Separated ☐Married ☐Divorced ☐Living with a partner ☐A6. How many years of full-time education did you complete?

A7. What is the highest educational level you obtained?

Primary school ☐Secondary school ☐School or college sixth form ☐College of Further Education ☐Polytechnic or University ☐Some other type of college ☐ Please specify _____A8. Are you a current user of tobacco ☐ or a former user of tobacco ☐or never used tobacco on a regular basis (1 tobacco product/day for a period of 1 year), ☐
if so tick the box and go to question A13A9. If you are a former tobacco user, how long ago did you stop using tobacco? yearsA10. At what age did you begin to use tobacco products? Years old

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

 a) Numbers of cigarettes per day? b) Numbers of hand rolled cigarettes per day? c) Numbers of pipes or cigars per day? d) Number of smokeless tobacco per day?

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

Study ID: _ _ / _ _ _ _

Patient Initials: _____

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

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

A14. Just before you became ill, how many alcoholic drinks did you have each week?

₁ Drinks

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

	a) Bottles of wine	b) Bottles of Spirits	c) Pints of beer/lager/cider
None	<input type="text"/> ₁	<input type="text"/> ₁	None <input type="text"/> ₁
Less than 1	<input type="text"/> ₂	<input type="text"/> ₂	Less than 7 <input type="text"/> ₂
1	<input type="text"/> ₃	<input type="text"/> ₃	7-14 <input type="text"/> ₃
2-3	<input type="text"/> ₄	<input type="text"/> ₄	15-21 <input type="text"/> ₄
4-6	<input type="text"/> ₅	<input type="text"/> ₅	22-28 <input type="text"/> ₅
7-10	<input type="text"/> ₆	<input type="text"/> ₆	28-35 <input type="text"/> ₆
11 or more	<input type="text"/> ₇	<input type="text"/> ₇	36 or more <input type="text"/> ₇

A16. What brand of alcohol do you/did 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

A19. What was the occupation/job which you had for the longest time in your life?
_____ ₁

A20. Have you ever been unemployed? Yes ☐ ₁ No ☐ ₂

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

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

Study ID: __ / __ - __ - __

Patient Initials: _____

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 ☐ ₂ 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 <input type="checkbox"/> ₁	Financial concerns <input type="checkbox"/> ₂	Staying in work/college <input type="checkbox"/> ₃
Cost of attending appointments <input type="checkbox"/> ₄	Taking time off work/college <input type="checkbox"/> ₅	Returning to work/college <input type="checkbox"/> ₆

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

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

A25. By placing a tick in one box in each group below, please indicate which statements best describes your own health state today

a) Mobility

I have no problems walking about	<input type="checkbox"/> ₁
I have some problems walking about	<input type="checkbox"/> ₂
I am confined to bed	<input type="checkbox"/> ₃

b) Self care

I have no problems with self care	<input type="checkbox"/> ₁
I have some problems with washing and dressing myself	<input type="checkbox"/> ₂
I am unable to wash and dress myself	<input type="checkbox"/> ₃

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

I have no problems with performing my usual activities	<input type="checkbox"/> ₁
I have some problems with performing my usual activities	<input type="checkbox"/> ₂
I am unable to perform my usual activities	<input type="checkbox"/> ₃

Study ID: __ __ / __ __ __ __

Patient Initials: _____

d) Pain discomfort

I have no pain or discomfort

☐ ₁

I have moderate pain or discomfort

☐ ₂

I have extreme pain or discomfort

☐ ₃**e) Anxiety/depression**

I am not anxious or depressed

☐ ₁

I am moderately anxious or depressed

☐ ₂

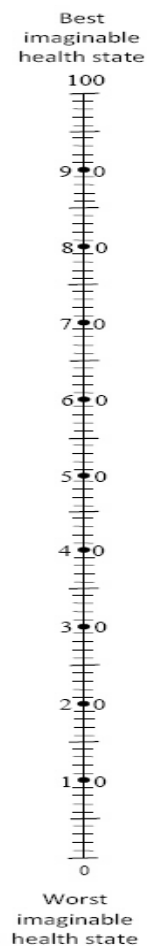
I am extremely anxious or depressed

☐ ₃

A26. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the **best state** you can imagine is marked 100 and the **worst state** you can imagine is marked 0. We would like you to indicate in relation to this scale how good or bad your own health is today, in your opinion. Please do this by writing the number in the box below to indicate which point on the scale that describes how good or bad your health state is today.

100 = best state

0 = worst state

 ₁

B.2.2 Main Questionnaire Pack

Study number:

		B			
--	--	---	--	--	--

v.1.1

headandneck
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Questionnaire pack – Baseline

Thank you again 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 primary investigator (details below).

In the unlikely event that some people may find some of the questions intrusive or upsetting, please contact the primary investigator that will respond to your concerns and provide appropriate support.

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
School of Oral and Dental Science
Bristol Dental School
Lower Maudlin Street
Bristol BS1 2LY
Telephone: 0117 342 4149
E-mail: headandneck5000@uhbristol.nhs.uk



Questionnaire pack – Baseline

Version 4.1
16 July 2010

Study number: **B**

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 question influence your response to other questions. There are no right or wrong answers.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
B1. In uncertain times, I usually expect the best.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B2. It's easy for me to relax.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B3. If something can go wrong for me, it will.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B4. I'm always optimistic about my future	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B5. I enjoy my friends a lot.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B6. It's important for me to keep busy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B7. I hardly ever expect things to go my way.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B8. I don't get upset too easily.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B9. I rarely count on good things happening to me.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
B10. Overall, I expect more good things to happen to me than bad.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> 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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C2 Do you have any trouble taking a <u>long</u> walk?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

C4	Do you need to stay in bed or a chair during the day?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C5	Do you need help with eating, dressing, washing yourself or using the toilet?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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During the past week:		Not at all	A little	Quite a bit	Very Much
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C6	Were you limited in doing either your work or other daily activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C7	Were you limited in pursuing your hobbies or other leisure time activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C8	Were you short of breath?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C9	Have you had pain?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C10	Did you need to rest?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C11	Have you had trouble sleeping?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C12	Have you felt weak?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C13	Have you lacked appetite?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
-----	---------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

During the past week:		Not at all	A little	Quite a bit	Very Much
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C14	Have you felt nauseated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C15	Have you vomited?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
-----	-------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

C16	Have you been constipated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C17	Have you had diarrhoea?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C18	Were you tired?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C21	Did you feel tense?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C22	Did you worry?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C23	Did you feel irritable?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C24	Did you feel depressed?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C25	Have you had difficulty remembering things?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C26	Has your physical condition or medical treatment interfered with your <u>family</u> life?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C27	Has your physical condition or medical treatment interfered with your <u>social</u> activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C28	Has your physical condition or medical treatment interfered caused you financial difficulties?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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 <u>health</u> during the past week?								
	Very poor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Excellent
C30	How would you rate your overall <u>quality of life</u> during the past week?								
	Very poor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Excellent

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Specific Aspects of Your Health

We are interested in some things about you and specific aspects of 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.

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

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

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		Yes	No
D31	Have you used painkillers?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D32	Have you taken any nutritional supplements (excluding vitamins)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D33	Have you used a feeding tube?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D34	Have you lost weight?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D35	Have you gained weight?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

Your Feelings

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

E1 I feel tense or 'wound up':

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

E2 I still enjoy the things I used to enjoy:

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

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

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

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

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

E5 Worrying thoughts go through my mind:

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

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E6 I feel cheerful:

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

E7 I can sit at ease and feel relaxed:

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

E8 I feel as if I am slowed down:

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

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

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

E10 I have lost interest in my appearance:

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

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

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

E12 I look forward with enjoyment to things:

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

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5000**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

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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

Thank you for
completing the questionnaire

B.2.3 Supplementary Questionnaire Pack (Bristol only)

Study number: **B** headandneck
5000**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

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.

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.

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5000**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.
- ☐₄ I cannot work due to problems with my shoulder.

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.

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5000**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.

- | | | |
|--|--|--|
| <input type="checkbox"/> ₁ Pain | <input type="checkbox"/> ₅ Swallowing | <input type="checkbox"/> ₉ Taste |
| <input type="checkbox"/> ₂ Appearance | <input type="checkbox"/> ₆ Chewing | <input type="checkbox"/> ₁₀ Saliva |
| <input type="checkbox"/> ₃ Activity | <input type="checkbox"/> ₇ Speech | <input type="checkbox"/> ₁₁ Mood |
| <input type="checkbox"/> ₄ Recreation | <input type="checkbox"/> ₈ Shoulder | <input type="checkbox"/> 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

I15. In general, would you say your *health-related quality of life* during the past 7 days 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* during the past 7 days. (Tick one box: ☒)

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

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I17A. 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 difficulty	Quite a bit of difficulty	Very much difficulty
J1	Have you had any difficulty maintaining your independence?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J2	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J3	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J4	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J5	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J6	Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J7	Have you had any financial difficulties?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J8	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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During the past month:		No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
J9	Have you had any difficulty concerning your work? (or education if you are a student)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J11	Have you had any difficulty communicating with those closest to you? (e.g. partner, children, parents)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J12	Have you had difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J13	Have you had any difficulty concerning sexual matters?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J14	Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J15	Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J16	Have you felt isolated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J17	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J18	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J19	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J20	Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J21	Have you had any difficulty with any other area of your everyday life?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Study number: **B** headandneck
5000**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

K3B My self-consciousness makes me irritable at home:

N/A ☐₁

Never/Almost never ☐₂

Sometimes ☐₃

Often ☐₄

Almost always ☐₅

Study number: **B** headandneck
5000**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

Study number: **B** headandneck
5000**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

Study number: **B** headandneck
5000**K24B I avoid going to pubs/restaurants:**

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

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 | | | | Moderately | | | Extremely |
| noticeable | | | | Noticeable | | | Noticeable |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ | <input type="checkbox"/> ₆ | <input type="checkbox"/> ₇ | |

K4C How much will your treatment change the way you look?

- | | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Not at all | | | | Very much |
| 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |

K6C How much does this bother you?

- | | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Not at all | | | | Very much so |
| 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |

Thank you for
completing the questionnaire

B.2.4 Sexual History Questionnaire

headandneck 5000

As part of the head and neck 5000 research study you agreed to take part in, there are some additional questions we would like to ask you. There is some new evidence that a small number of head and neck cancers may be related to a virus, which could be sexually transmitted. To better understand this process, we wish to gather information about all head and neck cancer patient's sexual history. We have a few questions for you about your sexual history, which will take about 2 minutes to answer. While we understand that this is a very sensitive topic, we would appreciate it if you would be willing to answer the questions on the following page. If you find a question upsetting, you always have the option of skipping it. Only the research team has access to your answers and we will keep this information confidential.

Thank you

Professor Andy Ness

Study number: **B**

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Sexual History

1. How old were you when you first had sexual intercourse? _____¹ Years

2. How many different sexual partners have you had in your lifetime? _____¹

3A. Have you ever performed oral sex on a partner? **Yes** **No**
☐¹ ☐²

If no, please skip to question 4 below

3B. If yes, how many different sexual partners have you performed oral sex on? _____¹

4. Have you ever had sex with a same sex partner? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

If no, please skip to question 5 below

4B. If yes, how many different same sex partners have you had in your lifetime? _____¹

5. Have you ever been diagnosed or treated for genital warts? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

6. Have you ever had a sexual partner who had genital warts? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

7A. If female, have you ever had an abnormal pap smear? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

7B. If male, have any of your sexual partners ever had an abnormal pap smear? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

8A. If female, have you ever been diagnosed with cervical cancer? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

8B. If male, have any of your sexual partners ever been diagnosed with cervical cancer? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

9. If male, are you circumcised? **Yes** **No** **Don't Know**
☐¹ ☐² ☐³

B.3 4-months

B.3.1 Data Capture Form

Study ID number

Participant Initials

MONTH 4

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A – BASIC DATA					
A1. DATE OF 4 MONTH DATA COLLECTION (day/month/year)			A2. PATIENT ALIVE		
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>
B – TREATMENT					
B1. ACTUAL CANCER PLAN INTENT					
A. Curative <input type="checkbox"/>		B. Palliative anti-cancer <input type="checkbox"/>		C. Supportive <input type="checkbox"/>	
D. No specific anti-cancer <input type="checkbox"/>					
B2. ACTUAL CANCER TREATMENT TYPE RECEIVED (Please, tick all that apply)					
A. Surgery (primary site) <input type="checkbox"/>		B. Surgery (neck) <input type="checkbox"/>			
C. Teletherapy (Radiotherapy) <input type="checkbox"/>		D. Chemotherapy <input type="checkbox"/>			
E. Hormone therapy <input type="checkbox"/>		F. Specialist palliative <input type="checkbox"/>			
G. Brachytherapy <input type="checkbox"/>		H. Biological <input type="checkbox"/>			
I. Other <input type="checkbox"/>		J. Active monitoring <input type="checkbox"/>			
K. Combined chemoradiotherapy <input type="checkbox"/>		L. Reconstruction with free flap <input type="checkbox"/>			
B3. TREATMENT TYPE SEQUENCE 1. <input type="text"/> 2. <input type="text"/> 3. <input type="text"/> 4. <input type="text"/> 5. <input type="text"/>					
B10. PROCEDURE/TREATMENT START DATE <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>					
B4. CO-MORBIDITY INDEX					
A. No co-morbidity <input type="checkbox"/>		B. Mild decompensation <input type="checkbox"/>		C. Moderate decompensation <input type="checkbox"/>	
D. Severe decompensation <input type="checkbox"/>		E. Unknown <input type="checkbox"/>			
B5. DEFINITIVE PRE TREATMENT STAGING A. DATE: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>					
B. T <input type="text"/> <input type="text"/> <input type="text"/>		C. N <input type="text"/> <input type="text"/> <input type="text"/>		D. M <input type="text"/>	
B5a. PATHOLOGICAL TNM STAGING (If applicable) A. DATE: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>					
B. pT <input type="text"/> <input type="text"/> <input type="text"/>		C. pN <input type="text"/> <input type="text"/> <input type="text"/>		D. pM <input type="text"/>	
B11. WAS THE PRESCRIBED RADIOTHERAPY TREATMENT COMPLETED? (if prescribed at diagnosis)					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>		C. Ongoing <input type="checkbox"/>	
D. Not applicable <input type="checkbox"/>					
B11a. If Radiotherapy not completed please give reason:					
A. Toxicity/side effects <input type="checkbox"/>		B. Altered treatment plan <input type="checkbox"/>		C. Patient choice <input type="checkbox"/>	
D. other <input type="checkbox"/>					
B12. WAS THE PRESCRIBED CHEMOTHERAPY TREATMENT COMPLETED? (if prescribed at diagnosis)					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>		C. Ongoing <input type="checkbox"/>	
D. Not applicable <input type="checkbox"/>					
B12a. If Chemotherapy not completed please give reason:					
A. Toxicity/side effects <input type="checkbox"/>		B. Altered treatment plan <input type="checkbox"/>		C. Patient choice <input type="checkbox"/>	
D. Not applicable <input type="checkbox"/>					
B13. DOES THE PATIENT HAVE A PEG? A. Yes <input type="checkbox"/> B. No <input type="checkbox"/>					
B14. APPROXIMATELY HOW MUCH FEEDING IS THROUGH THE PEG?					
A. None <input type="checkbox"/>		B. < 20% <input type="checkbox"/>		C. 20 – 80% <input type="checkbox"/>	
D. > 80% <input type="checkbox"/>					
B15. DOES THE PATIENT HAVE A TRACHEOSTOMY? A. <input type="checkbox"/> B. No <input type="checkbox"/>					
B16. HAS THERE BEEN TUMOUR RECURRENCE? A. Yes <input type="checkbox"/> B. No <input type="checkbox"/> C. N/A <input type="checkbox"/>					
If YES what is the staging of the recurrence?		A. T <input type="text"/> <input type="text"/> <input type="text"/>		B. N <input type="text"/> <input type="text"/> <input type="text"/>	
C. M <input type="text"/>					
C – OTHER					
C1. PATIENT TRIAL STATUS (for other trials)			A. Eligible and entered <input type="checkbox"/>		
			B. Eligible, declined <input type="checkbox"/>		
C. Eligible, not approached <input type="checkbox"/>			D. Ineligible <input type="checkbox"/>		
			E. Not applicable <input type="checkbox"/>		

C2. COMMENTS:

Adult Comorbidity Evaluation-27

Identify the important medical comorbidities and grade severity using the index.
Overall Comorbidity Score is defined according to the highest ranked single ailment, except in the case where two or more Grade 2 ailments occur in different organ systems. In this situation, the overall comorbidity score should be designated Grade 3.

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Cardiovascular system			
Myocardial Infarct	<input type="checkbox"/> MI \leq 6 months	<input type="checkbox"/> MI $>$ 6 months ago	<input type="checkbox"/> MI by ECG only, age undetermined
Angina / Coronary Artery Disease	<input type="checkbox"/> Unstable angina	<input type="checkbox"/> Chronic exertional angina <input type="checkbox"/> Recent (\leq 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty (PTCA) <input type="checkbox"/> Recent (\leq 6 months) coronary stent	<input type="checkbox"/> ECG or stress test evidence or catheterization evidence of coronary disease without symptoms <input type="checkbox"/> Angina pectoris not requiring hospitalization <input type="checkbox"/> CABG or PTCA ($>$ 6 mos.) <input type="checkbox"/> Coronary stent ($>$ 6 mos.)
Congestive Heart Failure (CHF)	<input type="checkbox"/> Hospitalized for CHF within past 6 months <input type="checkbox"/> Ejection fraction $<$ 20%	<input type="checkbox"/> Hospitalized for CHF $>$ 6 months prior <input type="checkbox"/> CHF with dyspnea which limits activities	<input type="checkbox"/> CHF with dyspnea which has responded to treatment <input type="checkbox"/> Exertional dyspnea <input type="checkbox"/> Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	<input type="checkbox"/> Ventricular arrhythmia \leq 6 months	<input type="checkbox"/> Ventricular arrhythmia $>$ 6 months <input type="checkbox"/> Chronic atrial fibrillation or flutter <input type="checkbox"/> Pacemaker	<input type="checkbox"/> Sick Sinus Syndrome <input type="checkbox"/> Supraventricular tachycardia
Hypertension	<input type="checkbox"/> DBP $>$ 130 mm Hg <input type="checkbox"/> Severe malignant papilledema or other eye changes <input type="checkbox"/> Encephalopathy	<input type="checkbox"/> DBP 115-129 mm Hg <input type="checkbox"/> DBP 90-114 mm Hg while taking antihypertensive medications <input type="checkbox"/> Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	<input type="checkbox"/> DBP 90-114 mm Hg while not taking antihypertensive medications <input type="checkbox"/> DBP $<$ 90 mm Hg while taking antihypertensive medications <input type="checkbox"/> Hypertension, not otherwise specified
Venous Disease	<input type="checkbox"/> Recent PE (\leq 6 mos.) <input type="checkbox"/> Use of venous filter for PE's	<input type="checkbox"/> DVT controlled with Coumadin or heparin <input type="checkbox"/> Old PE $>$ 6 months	<input type="checkbox"/> Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency $<$ 6 months ago <input type="checkbox"/> Untreated thoracic or abdominal aneurysm ($>$ 6 cm)	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency $>$ 6 months ago <input type="checkbox"/> Chronic insufficiency	<input type="checkbox"/> Intermittent claudication <input type="checkbox"/> Untreated thoracic or abdominal aneurysm ($<$ 6 cm) <input type="checkbox"/> s/p abdominal or thoracic aortic aneurysm repair
Respiratory System			
	<input type="checkbox"/> Marked pulmonary insufficiency <input type="checkbox"/> Restrictive Lung Disease or COPD with dyspnea at rest despite treatment <input type="checkbox"/> Chronic supplemental O ₂ <input type="checkbox"/> CO ₂ retention (pCO ₂ $>$ 50 torr) <input type="checkbox"/> Baseline pO ₂ $<$ 50 torr <input type="checkbox"/> FEV1 ($<$ 50%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities <input type="checkbox"/> FEV1 (51%-65%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment <input type="checkbox"/> FEV1 (66%-80%)
Gastrointestinal System			
Hepatic	<input type="checkbox"/> Portal hypertension and/or esophageal bleeding \leq 6 mos. (Encephalopathy, Ascites, Jaundice with Total Bilirubin $>$ 2)	<input type="checkbox"/> Chronic hepatitis, cirrhosis, portal hypertension with moderate symptoms "compensated hepatic failure"	<input type="checkbox"/> Chronic hepatitis or cirrhosis without portal hypertension <input type="checkbox"/> Acute hepatitis without cirrhosis <input type="checkbox"/> Chronic liver disease manifested on biopsy or persistently elevated bilirubin ($>$ 3 mg/dl)
Stomach / Intestine	<input type="checkbox"/> Recent ulcers (\leq 6 months ago) requiring blood transfusion	<input type="checkbox"/> Ulcers requiring surgery or transfusion $>$ 6 months ago	<input type="checkbox"/> Diagnosis of ulcers treated with meds <input type="checkbox"/> Chronic malabsorption syndrome <input type="checkbox"/> Inflammatory bowel disease (IBD) on meds or h/o with complications and/or surgery
Pancreas	<input type="checkbox"/> Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	<input type="checkbox"/> Uncomplicated acute pancreatitis <input type="checkbox"/> Chronic pancreatitis with minor complications (malabsorption, impaired glucose tolerance, or GI bleeding)	<input type="checkbox"/> Chronic pancreatitis w/o complications

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Renal System			
End-stage renal disease	<input type="checkbox"/> Creatinine > 3 mg% with multi-organ failure, shock, or sepsis <input type="checkbox"/> Acute dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine >3 mg% <input type="checkbox"/> Chronic dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine 2-3 mg%.
Endocrine System (Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)			
Diabetes Mellitus	<input type="checkbox"/> Hospitalization ≤ 6 months for DKA <input type="checkbox"/> Diabetes causing end-organ failure <input type="checkbox"/> retinopathy <input type="checkbox"/> neuropathy <input type="checkbox"/> nephropathy* <input type="checkbox"/> coronary disease* <input type="checkbox"/> peripheral arterial disease*	<input type="checkbox"/> IDDM without complications <input type="checkbox"/> Poorly controlled AODM with oral agents	<input type="checkbox"/> AODM controlled by oral agents only
Neurological System			
Stroke	<input type="checkbox"/> Acute stroke with significant neurologic deficit	<input type="checkbox"/> Old stroke with neurologic residual	<input type="checkbox"/> Stroke with no residual <input type="checkbox"/> Past or recent TIA
Dementia	<input type="checkbox"/> Severe dementia requiring full support for activities of daily living	<input type="checkbox"/> Moderate dementia (not completely self-sufficient, needs supervising)	<input type="checkbox"/> Mild dementia (can take care of self)
Paralysis	<input type="checkbox"/> Paraplegia or hemiplegia requiring full support for activities of daily living	<input type="checkbox"/> Paraplegia or hemiplegia requiring wheelchair, able to do some self care	<input type="checkbox"/> Paraplegia or hemiplegia, ambulatory and providing most of self care
Neuromuscular	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care
Psychiatric			
	<input type="checkbox"/> Recent suicidal attempt <input type="checkbox"/> Active schizophrenia	<input type="checkbox"/> Depression or bipolar disorder uncontrolled <input type="checkbox"/> Schizophrenia controlled w/ meds	<input type="checkbox"/> Depression or bipolar disorder controlled w/ medication
Rheumatologic (Incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)			
	<input type="checkbox"/> Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)	<input type="checkbox"/> Connective Tissue Disorder on steroids or immunosuppressant medications	<input type="checkbox"/> Connective Tissue Disorder on NSAIDs or no treatment
Immunological System (AIDS should not be considered a comorbidity for Kaposi's Sarcoma or Non-Hodgkin's Lymphoma)			
AIDS	<input type="checkbox"/> Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)	<input type="checkbox"/> HIV+ with h/o defining illness. CD4+ < 200/μL	<input type="checkbox"/> Asymptomatic HIV+ patient. <input type="checkbox"/> HIV+ w/o h/o AIDS defining illness. CD4+ > 200/μL
Malignancy (Excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)			
Solid Tumor including melanoma	<input type="checkbox"/> Uncontrolled cancer <input type="checkbox"/> Newly diagnosed but not yet treated <input type="checkbox"/> Metastatic solid tumor	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated within the last 5 years	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated > 5 years ago
Leukemia and Myeloma	<input type="checkbox"/> Relapse <input type="checkbox"/> Disease out of control	<input type="checkbox"/> 1st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o leukemia or myeloma with last Rx > 1 yr prior
Lymphoma	<input type="checkbox"/> Relapse	<input type="checkbox"/> 1st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o lymphoma w/ last Rx >1 yr prior
Substance Abuse (Must be accompanied by social, behavioral, or medical complications)			
Alcohol	<input type="checkbox"/> Delirium tremens	<input type="checkbox"/> Active alcohol abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o alcohol abuse but not presently drinking
Illicit Drugs	<input type="checkbox"/> Acute Withdrawal Syndrome	<input type="checkbox"/> Active substance abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o substance abuse but not presently using
Body Weight			
Obesity	<input type="checkbox"/> Morbid (i.e., BMI ≥ 38)		

OVERALL COMORBIDITY SCORE (circle one.) **0** **1** **2** **3** **9**

None Mild Moderate Severe Unknown

B.3.2 Main Questionnaire Pack

Study number:

		F			
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headandneck
5000

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5000

Questionnaire pack – 4 month

Thank you for continuing to take part in this study

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

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

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

In the unlikely event that some people may find some of the questions intrusive or upsetting, please contact the primary investigator that will respond to your concerns and provide appropriate support.

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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Study number:

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Questionnaire pack – 4 months

Version 5.0
02 January 2012

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About You

A1. Date (day/month/year) / / A2. What is your date of birth? (day/month/year) / / A4. What is your current weight? ₁ Kg OR ₂ Stone ₂ lbs

A5. Are you currently?

Single	<input type="text"/> ₁	Widowed	<input type="text"/> ₂	Separated	<input type="text"/> ₃
Married	<input type="text"/> ₄	Divorced	<input type="text"/> ₅	Living with a partner	<input type="text"/> ₆

A8. Are you a current user of tobacco ₁ or have you recently quit using tobacco or never used tobacco, if so go to question A13 ₂

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/did you normally smoke?

 ₁
A13. In a typical week how many days do you drink alcohol? Please enter number of days in box ₁If none, tick the box and go to question A17 ₂

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

	a) Bottles of wine	b) Bottles of Spirits	c) Pints of beer/lager/cider
None	<input type="text"/> ₁	<input type="text"/> ₁	None <input type="text"/> ₁
Less than 1	<input type="text"/> ₂	<input type="text"/> ₂	Less than 7 <input type="text"/> ₂
1	<input type="text"/> ₃	<input type="text"/> ₃	7-14 <input type="text"/> ₃
2-3	<input type="text"/> ₄	<input type="text"/> ₄	15-21 <input type="text"/> ₄
4-6	<input type="text"/> ₅	<input type="text"/> ₅	22-28 <input type="text"/> ₅
7-10	<input type="text"/> ₆	<input type="text"/> ₆	28-35 <input type="text"/> ₆
11 or more	<input type="text"/> ₇	<input type="text"/> ₇	36 or more <input type="text"/> ₇

A16. What brand of alcohol do you/did you normally drink?

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

<u>Weekly income before tax</u>	<u>Annual income before tax</u>
Less than £77 <input type="checkbox"/> ₁	Less than £3999 <input type="checkbox"/> ₉
£77 - £154 <input type="checkbox"/> ₂	£4000 - £7999 <input type="checkbox"/> ₁₀
£155 - £230 <input type="checkbox"/> ₃	£8000 - £11999 <input type="checkbox"/> ₁₁
£231 - £346 <input type="checkbox"/> ₄	£12000 - £17999 <input type="checkbox"/> ₁₂
£347 - £442 <input type="checkbox"/> ₅	£18000 - £22999 <input type="checkbox"/> ₁₃
£443 - £558 <input type="checkbox"/> ₆	£23000 - £28999 <input type="checkbox"/> ₁₄
£559 - £673 <input type="checkbox"/> ₇	£29000 - £34999 <input type="checkbox"/> ₁₅
£674 or more <input type="checkbox"/> ₈	£35000 or more <input type="checkbox"/> 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 ☐ ₂ 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 <input type="checkbox"/> ₁	Financial concerns <input type="checkbox"/> ₂	Staying in work/college <input type="checkbox"/> ₃
Cost of attending appointments <input type="checkbox"/> ₄	Taking time off work/college <input type="checkbox"/> ₅	Returning to work/college <input type="checkbox"/> ₆

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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 question influence your response to other questions. There are no right or wrong answers.

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

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C2	Do you have any trouble taking a <u>long</u> walk?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
		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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C4	Do you need to stay in bed or a chair during the day?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C5	Do you need help with eating, dressing, washing yourself or using the toilet?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C7	Were you limited in pursuing your hobbies or other leisure time activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C8	Were you short of breath?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C9	Have you had pain?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C10	Did you need to rest?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C11	Have you had trouble sleeping?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C12	Have you felt weak?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C13	Have you lacked appetite?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
During the past week:		Not at all	A little	Quite a bit	Very Much
C14	Have you felt nauseated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C15	Have you vomited?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C16	Have you been constipated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
C17	Have you had diarrhoea?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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C18	Were you tired?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C21	Did you feel tense?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
-----	---------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

C22	Did you worry?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C23	Did you feel irritable?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
-----	-------------------------	---------------------------------------	---------------------------------------	---------------------------------------	---------------------------------------

C24	Did you feel depressed?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C25	Have you had difficulty remembering things?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C26	Has your physical condition or medical treatment interfered with your <u>family</u> life?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C27	Has your physical condition or medical treatment interfered with your <u>social</u> activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C28	Has your physical condition or medical treatment interfered caused you financial difficulties?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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For the following questions please tick the box between 1 and 7 that best applies to you

C29	How would you rate your overall <u>health</u> during the past week?								
	Very poor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Excellent

C30	How would you rate your overall <u>quality of life</u> during the past week?								
	Very poor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Excellent

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We are interested in some things about you and specific aspects of 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.

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

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

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D30 Have you felt less sexual enjoyment?

☐ ₁☐ ₂☐ ₃☐ ₄**During the past week:****Yes****No**

D31 Have you used painkillers?

☐ ₁☐ ₂D32 Have you taken any nutritional supplements
(excluding vitamins)?☐ ₁☐ ₂

D33 Have you used a feeding tube?

☐ ₁☐ ₂

D34 Have you lost weight?

☐ ₁☐ ₂

D35 Have you gained weight?

☐ ₁☐ ₂**Your Feelings**

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

E1 I feel tense or 'wound up':☐ ₁

Most of the time

☐ ₂

A lot of the time

☐ ₃

From time to time, occasionally

☐ ₄

Not at all

E2 I still enjoy the things I used to enjoy:☐ ₁

Definitely as much

☐ ₂

Not quite so much

☐ ₃

Only a little

☐ ₄

Hardly at all

E3 I get a sort of frightened feeling as if something awful is about to happen:☐ ₁

Very definitely and quite badly

☐ ₂

Yes, but not too badly

☐ ₃

A little, but it doesn't worry me

☐ ₄

Not at all

E4 I can laugh and see the funny side of things:☐ ₁

As much as I always could

☐ ₂

Not quite so much now

☐ ₃

Definitely not so much now

☐ ₄

Not at all

E5 Worrying thoughts go through my mind:

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

E6 I feel cheerful:

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

E7 I can sit at ease and feel relaxed:

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

E8 I feel as if I am slowed down:

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

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

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

E10 I have lost interest in my appearance:

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

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

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

E12 I look forward with enjoyment to things:

- ☐ ₁ As much as I ever did

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- ☐ 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

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- ☐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 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

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*

*Please tick
as appropriate
NA – not applicable

If yes, please indicate

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H1. Paid for any kind of medication ? (e.g. conventional, alternative)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	Type(s) of medication _____a
				Approximate amount £ _____b

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

H2. Paid for any kind of treatment , i.e. private health care? (e.g. conventional, alternative)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	Type(s) of treatment _____a
				Approximate amount £ _____b

H3. Paid for home help ?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	Approximate amount £ _____a
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H4. Incurred any travel expenses for your hospital/clinic appointments? (e.g. train fares, bus fares, petrol, parking costs, overnight accommodation)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	Approximate amount £ _____a
--	---------------------------------------	---------------------------------------	---------------------------------------	--------------------------------

H5. Incurred any other out-of-pocket expenses ? (e.g. special dietary items, pain relief)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	Type(s) of expenditure _____a
				Approximate amount £ _____b

H6. Have you taken time off work because of your illness?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	For you 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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	For your family Number of weeks or months (delete as appropriate) _____a

H8. Have you suffered any reduction of income as a result of taking time off work because of your illness?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	For you Approximate amount of gross income that has been lost in total £ _____a
---	---------------------------------------	---------------------------------------	---------------------------------------	---

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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

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

£ ______a

Thank you for
completing the questionnaire

B.3.3 Supplementary Questionnaire Pack (Bristol only)

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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

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 he/she 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

£ _____ 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.

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- ☐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.

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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.

- | | | |
|--|--|--|
| <input type="checkbox"/> ₁ Pain | <input type="checkbox"/> ₅ Swallowing | <input type="checkbox"/> ₉ Taste |
| <input type="checkbox"/> ₂ Appearance | <input type="checkbox"/> ₆ Chewing | <input type="checkbox"/> ₁₀ Saliva |
| <input type="checkbox"/> ₃ Activity | <input type="checkbox"/> ₇ Speech | <input type="checkbox"/> ₁₁ Mood |
| <input type="checkbox"/> ₄ Recreation | <input type="checkbox"/> ₈ Shoulder | <input type="checkbox"/> 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: F headandneck
5000**I15. In general, would you say your *health-related quality of life* during the past 7 days 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* during the past 7 days. (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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J2	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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	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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J4	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J5	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J6	Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J7	Have you had any financial difficulties?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J8	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J9	Have you had any difficulty concerning your work? (or education if you are a student)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J11	Have you had any difficulty communicating with those closest to you? (e.g. partner, children, parents)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J12	Have you had difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J13	Have you had any difficulty concerning sexual matters?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J14	Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J15	Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J16	Have you felt isolated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J17	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J18	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J20	Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J21	Have you had any difficulty with any other area of your everyday life?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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

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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

Study number: **F** headandneck
5000**K19B How distressed do you get when going to social events?**N/A ☐ ₁Not at all ☐ ₂Moderately ☐ ₃A fair amount ☐ ₄Extremely ☐ ₅**K20B How normal do you feel?**Not at all ☐ ₁Slightly ☐ ₂Moderately ☐ ₃Extremely ☐ ₄**K21B At present my self-consciousness has an adverse effect on my sex life:**Almost always ☐ ₁Often ☐ ₂Sometimes ☐ ₃Never/almost never ☐ ₄N/A ☐ ₅**K22B I avoid going out of the house:**Almost always ☐ ₁Often ☐ ₂Sometimes ☐ ₃Never/almost never ☐ ₄**K23B How distressed do you get when other people make remarks about the appearance of your head/neck?**N/A ☐ ₁Not at all ☐ ₂Moderately ☐ ₃A fair amount ☐ ₄Extremely ☐ ₅**K24B I avoid going to pubs/restaurants:**Almost always ☐ ₁Often ☐ ₂Sometimes ☐ ₃Never/almost never ☐ ₄N/A ☐ ₅

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5000**K1C My feature causes me physical pain/discomfort:**Never/almost never ☐ ₁Sometimes ☐ ₂Often ☐ ₃Almost always ☐ ₄**K2C My feature limits my physical ability to do the things I want to do:**Almost always ☐ ₁Often ☐ ₂Sometimes ☐ ₃Never/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
noticeableModerately
noticeableExtremely
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

B.4 12-months**B.4.1 Data Capture Form**

Study ID number

Participant Initials

MONTH 12

headandneck
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A – BASIC DATA					
A1. DATE OF 12 MONTH DATA COLLECTION (day/month/year)			A2. PATIENT ALIVE		
<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>			A. Yes <input type="checkbox"/> B. No <input type="checkbox"/>		
B – TREATMENT					
B1. CANCER PLAN OF ANY TREATMENT SINCE MONTH 4					
A. Curative <input type="checkbox"/>		B. Palliative anti-cancer <input type="checkbox"/>		C. Supportive <input type="checkbox"/> D. No specific anti-cancer <input type="checkbox"/>	
B2. FURTHER CANCER TREATMENT TYPE RECEIVED SINCE MONTH 4 (Please, tick all that apply)					
A. Surgery (primary site) <input type="checkbox"/>		B. Surgery (neck) <input type="checkbox"/>			
C. Teletherapy (Radiotherapy) <input type="checkbox"/>		D. Chemotherapy <input type="checkbox"/>			
E. Hormone therapy <input type="checkbox"/>		F. Specialist palliative <input type="checkbox"/>			
G. Brachytherapy <input type="checkbox"/>		H. Biological <input type="checkbox"/>			
I. Other <input type="checkbox"/>		J. Active monitoring <input type="checkbox"/>			
K. Combined chemoradiotherapy <input type="checkbox"/>		L. Reconstruction with free flap <input type="checkbox"/>			
B3. TREATMENT TYPE SEQUENCE		1. <input type="text"/>	2. <input type="text"/>	3. <input type="text"/>	4. <input type="text"/> 5. <input type="text"/>
B10. PROCEDURE/TREATMENT START DATE <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>					
B4. CO-MORBIDITY INDEX					
A. No co-morbidity <input type="checkbox"/>		B. Mild decompensation <input type="checkbox"/>		C. Moderate decompensation <input type="checkbox"/>	
D. Severe decompensation <input type="checkbox"/>		E. Unknown <input type="checkbox"/>			
B5. MOST RECENT TNM STAGING					
A. DATE: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>					
B. T <input type="text"/> <input type="text"/> <input type="text"/>		C. N <input type="text"/> <input type="text"/> <input type="text"/>		D. M <input type="text"/>	
B11. WAS THE INITIAL COURSE OF RADIOTHERAPY TREATMENT COMPLETED? (if prescribed at diagnosis)					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>		C. Ongoing <input type="checkbox"/> D. Not applicable <input type="checkbox"/>	
B11a. If Radiotherapy not completed please give reason:					
A.Toxicity/side effects <input type="checkbox"/>		B. Altered treatment plan <input type="checkbox"/>		C. Patient choice <input type="checkbox"/> D. other <input type="checkbox"/>	
B12: WAS THE INITIAL COURSE OF CHEMOTHERAPY TREATMENT COMPLETED? (if prescribed at diagnosis)					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>		C. Ongoing <input type="checkbox"/> D. Not applicable <input type="checkbox"/>	
B12a. If Chemotherapy therapy not completed please give reason:					
A.Toxicity/side effects <input type="checkbox"/>		B. Altered treatment plan <input type="checkbox"/>		C. Patient choice <input type="checkbox"/> D. other <input type="checkbox"/>	
B12b: WAS ANY FURTHER TREATMENT COURSE COMPLETED?					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>		C. Ongoing <input type="checkbox"/> D. Not applicable <input type="checkbox"/>	
B13. DOES THE PATIENT HAVE A PEG?					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>			
B14. APPROXIMATELY HOW MUCH FEEDING IS THROUGH THE PEG?					
A. None <input type="checkbox"/>		B. < 20% <input type="checkbox"/>		C. 20 – 80% <input type="checkbox"/> D. > 80% <input type="checkbox"/>	
B15. DOES THE PATIENT HAVE A TRACHEOSTOMY?					
A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/>			
B16. HAS THERE BEEN TUMOUR RECURRENCE?		A. Yes <input type="checkbox"/>		B. No <input type="checkbox"/> C. N/A <input type="checkbox"/>	
B16a If YES what is the staging of the recurrence?		B. T <input type="text"/> <input type="text"/> <input type="text"/>		C. <input type="text"/> <input type="text"/> <input type="text"/> D. M <input type="text"/>	

Section C is overleaf

C – OTHER		
C1. PATIENT TRIAL STATUS (for other trials)	A. Eligible and entered <input type="checkbox"/>	B. Eligible, declined <input type="checkbox"/>
C. Eligible, not approached <input type="checkbox"/>	D. Ineligible <input type="checkbox"/>	E. Not applicable <input type="checkbox"/>
C2. COMMENTS: _____		

Adult Comorbidity Evaluation-27

Identify the important medical comorbidities and grade severity using the index.
Overall Comorbidity Score is defined according to the highest ranked single ailment, except in the case where two or more Grade 2 ailments occur in different organ systems. In this situation, the overall comorbidity score should be designated Grade 3.

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Cardiovascular system			
Myocardial Infarct	<input type="checkbox"/> MI ≤ 6 months	<input type="checkbox"/> MI > 6 months ago	<input type="checkbox"/> MI by ECG only, age undetermined
Angina / Coronary Artery Disease	<input type="checkbox"/> Unstable angina	<input type="checkbox"/> Chronic exertional angina <input type="checkbox"/> Recent (≤ 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty(PTCA) <input type="checkbox"/> Recent (≤ 6 months) coronary stent	<input type="checkbox"/> ECG or stress test evidence or catheterization evidence of coronary disease without symptoms <input type="checkbox"/> Angina pectoris not requiring hospitalization <input type="checkbox"/> CABG or PTCA (>6 mos.) <input type="checkbox"/> Coronary stent (>6 mos.)
Congestive Heart Failure (CHF)	<input type="checkbox"/> Hospitalized for CHF within past 6 months <input type="checkbox"/> Ejection fraction < 20%	<input type="checkbox"/> Hospitalized for CHF >6 months prior <input type="checkbox"/> CHF with dyspnea which limits activities	<input type="checkbox"/> CHF with dyspnea which has responded to treatment <input type="checkbox"/> Exertional dyspnea <input type="checkbox"/> Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	<input type="checkbox"/> Ventricular arrhythmia ≤ 6 months	<input type="checkbox"/> Ventricular arrhythmia > 6 months <input type="checkbox"/> Chronic atrial fibrillation or flutter <input type="checkbox"/> Pacemaker	<input type="checkbox"/> Sick Sinus Syndrome <input type="checkbox"/> Supraventricular tachycardia
Hypertension	<input type="checkbox"/> DBP>130 mm Hg <input type="checkbox"/> Severe malignant papilledema or other eye changes <input type="checkbox"/> Encephalopathy	<input type="checkbox"/> DBP 115-129 mm Hg <input type="checkbox"/> DBP 90-114 mm Hg while taking antihypertensive medications <input type="checkbox"/> Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	<input type="checkbox"/> DBP 90-114 mm Hg while not taking antihypertensive medications <input type="checkbox"/> DBP <90 mm Hg while taking antihypertensive medications <input type="checkbox"/> Hypertension, not otherwise specified
Venous Disease	<input type="checkbox"/> Recent PE (≤ 6 mos.) <input type="checkbox"/> Use of venous filter for PE's	<input type="checkbox"/> DVT controlled with Coumadin or heparin <input type="checkbox"/> Old PE > 6 months	<input type="checkbox"/> Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency < 6 months ago <input type="checkbox"/> Untreated thoracic or abdominal aneurysm (>6 cm)	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency > 6 months ago <input type="checkbox"/> Chronic insufficiency	<input type="checkbox"/> Intermittent claudication <input type="checkbox"/> Untreated thoracic or abdominal aneurysm (< 6 cm) <input type="checkbox"/> s/p abdominal or thoracic aortic aneurysm repair
Respiratory System			
	<input type="checkbox"/> Marked pulmonary insufficiency <input type="checkbox"/> Restrictive Lung Disease or COPD with dyspnea at rest despite treatment <input type="checkbox"/> Chronic supplemental O2 <input type="checkbox"/> CO2 retention (pCO2 > 50 torr) <input type="checkbox"/> Baseline pO2 < 50 torr <input type="checkbox"/> FEV1 (< 50%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities <input type="checkbox"/> FEV1 (51%-65%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment <input type="checkbox"/> FEV1 (66%-80%)
Gastrointestinal System			
Hepatic	<input type="checkbox"/> Portal hypertension and/or esophageal bleeding ≤ 6 mos. (Encephalopathy, Ascites, Jaundice with Total Bilirubin > 2)	<input type="checkbox"/> Chronic hepatitis, cirrhosis, portal hypertension with moderate symptoms "compensated hepatic failure"	<input type="checkbox"/> Chronic hepatitis or cirrhosis without portal hypertension <input type="checkbox"/> Acute hepatitis without cirrhosis <input type="checkbox"/> Chronic liver disease manifested on biopsy or persistently elevated bilirubin (>3 mg/dl)
Stomach / Intestine	<input type="checkbox"/> Recent ulcers(≤ 6 months ago) requiring blood transfusion	<input type="checkbox"/> Ulcers requiring surgery or transfusion > 6 months ago	<input type="checkbox"/> Diagnosis of ulcers treated with meds <input type="checkbox"/> Chronic malabsorption syndrome <input type="checkbox"/> Inflammatory bowel disease (IBD) on meds or h/o with complications and/or surgery
Pancreas	<input type="checkbox"/> Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	<input type="checkbox"/> Uncomplicated acute pancreatitis <input type="checkbox"/> Chronic pancreatitis with minor complications (malabsorption, impaired glucose tolerance, or GI bleeding)	<input type="checkbox"/> Chronic pancreatitis w/o complications

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Renal System			
End-stage renal disease	<input type="checkbox"/> Creatinine > 3 mg% with multi-organ failure, shock, or sepsis <input type="checkbox"/> Acute dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine >3 mg% <input type="checkbox"/> Chronic dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine 2-3 mg%.
Endocrine System (Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)			
Diabetes Mellitus	<input type="checkbox"/> Hospitalization ≤ 6 months for DKA <input type="checkbox"/> Diabetes causing end-organ failure <input type="checkbox"/> retinopathy <input type="checkbox"/> neuropathy <input type="checkbox"/> nephropathy* <input type="checkbox"/> coronary disease* <input type="checkbox"/> peripheral arterial disease*	<input type="checkbox"/> IDDM without complications <input type="checkbox"/> Poorly controlled AODM with oral agents	<input type="checkbox"/> AODM controlled by oral agents only
Neurological System			
Stroke	<input type="checkbox"/> Acute stroke with significant neurologic deficit	<input type="checkbox"/> Old stroke with neurologic residual	<input type="checkbox"/> Stroke with no residual <input type="checkbox"/> Past or recent TIA
Dementia	<input type="checkbox"/> Severe dementia requiring full support for activities of daily living	<input type="checkbox"/> Moderate dementia (not completely self-sufficient, needs supervising)	<input type="checkbox"/> Mild dementia (can take care of self)
Paralysis	<input type="checkbox"/> Paraplegia or hemiplegia requiring full support for activities of daily living	<input type="checkbox"/> Paraplegia or hemiplegia requiring wheelchair, able to do some self care	<input type="checkbox"/> Paraplegia or hemiplegia, ambulatory and providing most of self care
Neuromuscular	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care
Psychiatric			
	<input type="checkbox"/> Recent suicidal attempt <input type="checkbox"/> Active schizophrenia	<input type="checkbox"/> Depression or bipolar disorder uncontrolled <input type="checkbox"/> Schizophrenia controlled w/ meds	<input type="checkbox"/> Depression or bipolar disorder controlled w/ medication
Rheumatologic (Incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)			
	<input type="checkbox"/> Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)	<input type="checkbox"/> Connective Tissue Disorder on steroids or immunosuppressant medications	<input type="checkbox"/> Connective Tissue Disorder on NSAIDS or no treatment
Immunological System (AIDS should not be considered a comorbidity for Kaposi's Sarcoma or Non-Hodgkin's Lymphoma)			
AIDS	<input type="checkbox"/> Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)	<input type="checkbox"/> HIV+ with h/o defining illness. CD4+ < 200/μL	<input type="checkbox"/> Asymptomatic HIV+ patient. <input type="checkbox"/> HIV+ w/o h/o AIDS defining illness. CD4+ > 200/μL
Malignancy (Excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)			
Solid Tumor including melanoma	<input type="checkbox"/> Uncontrolled cancer <input type="checkbox"/> Newly diagnosed but not yet treated <input type="checkbox"/> Metastatic solid tumor	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated within the last 5 years	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated > 5 years ago
Leukemia and Myeloma	<input type="checkbox"/> Relapse <input type="checkbox"/> Disease out of control	<input type="checkbox"/> 1st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o leukemia or myeloma with last Rx > 1 yr prior
Lymphoma	<input type="checkbox"/> Relapse	<input type="checkbox"/> 1st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o lymphoma w/ last Rx >1 yr prior
Substance Abuse (Must be accompanied by social, behavioral, or medical complications)			
Alcohol	<input type="checkbox"/> Delirium tremens	<input type="checkbox"/> Active alcohol abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o alcohol abuse but not presently drinking
Illicit Drugs	<input type="checkbox"/> Acute Withdrawal Syndrome	<input type="checkbox"/> Active substance abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o substance abuse but not presently using
Body Weight			
Obesity		<input type="checkbox"/> Morbid (i.e., BMI ≥ 38)	

OVERALL COMORBIDITY SCORE (circle one.) **0** **1** **2** **3** **9**

None Mild Moderate Severe Unknown

B.4.2 Main Questionnaire Pack

Study number:

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Questionnaire pack – 12 month

Thank you for continuing to take part in this study

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

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

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

In the unlikely event that some people may find some of the questions intrusive or upsetting, please contact the primary investigator that will respond to your concerns and provide appropriate support.

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
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Lower Maudlin Street
Bristol BS1 2LY
Telephone: 0117 342 4149
Email: headandneck5000@uhbristol.nhs.uk**

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Questionnaire pack – 12 month Bristol

Version 5.0
02 January 2012

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About You

A1. Date (day/month/year) / / A2. What is your date of birth? (day/month/year) / / A4. What is your current weight? ₁ Kg OR ₂ Stone ₂ lbs

A5. Are you currently?

Single	<input type="text"/> ₁	Widowed	<input type="text"/> ₂	Separated	<input type="text"/> ₃
Married	<input type="text"/> ₄	Divorced	<input type="text"/> ₅	Living with a partner	<input type="text"/> ₆

A8. Are you a current user of tobacco ₁ or have you recently quit using tobacco or never used tobacco, if so go to question A13 ₂

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/did you normally smoke?

_____ ₁A13. In a typical week how many days do you drink alcohol? Please enter number of days in box ₁If none, tick the box and go to question A17 ₂

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

a) Bottles of wine		b) Bottles of Spirits		c) Pints of beer/lager/cider	
None	<input type="text"/> ₁	<input type="text"/> ₁	None	<input type="text"/> ₁	
Less than 1	<input type="text"/> ₂	<input type="text"/> ₂	Less than 7	<input type="text"/> ₂	
1	<input type="text"/> ₃	<input type="text"/> ₃	7-14	<input type="text"/> ₃	
2-3	<input type="text"/> ₄	<input type="text"/> ₄	15-21	<input type="text"/> ₄	
4-6	<input type="text"/> ₅	<input type="text"/> ₅	22-28	<input type="text"/> ₅	
7-10	<input type="text"/> ₆	<input type="text"/> ₆	28-35	<input type="text"/> ₆	
11 or more	<input type="text"/> ₇	<input type="text"/> ₇	36 or more	<input type="text"/> ₇	

A16. What brand of alcohol do you/did you normally drink?

_____ ₁

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

<u>Weekly income before tax</u>	<u>Annual income before tax</u>
Less than £77 <input type="checkbox"/> ₁	Less than £3999 <input type="checkbox"/> ₉
£77 - £154 <input type="checkbox"/> ₂	£4000 - £7999 <input type="checkbox"/> ₁₀
£155 - £230 <input type="checkbox"/> ₃	£8000 - £11999 <input type="checkbox"/> ₁₁
£231 - £346 <input type="checkbox"/> ₄	£12000 - £17999 <input type="checkbox"/> ₁₂
£347 - £442 <input type="checkbox"/> ₅	£18000 - £22999 <input type="checkbox"/> ₁₃
£443 - £558 <input type="checkbox"/> ₆	£23000 - £28999 <input type="checkbox"/> ₁₄
£559 - £673 <input type="checkbox"/> ₇	£29000 - £34999 <input type="checkbox"/> ₁₅
£674 or more <input type="checkbox"/> ₈	£35000 or more <input type="checkbox"/> 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 ☐ ₂ 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 <input type="checkbox"/> ₁	Financial concerns <input type="checkbox"/> ₂	Staying in work/college <input type="checkbox"/> ₃
Cost of attending appointments <input type="checkbox"/> ₄	Taking time off work/college <input type="checkbox"/> ₅	Returning to work/college <input type="checkbox"/> ₆

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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 question influence your response to other questions. There are no right or wrong answers.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
B1. In uncertain times, I usually expect the best.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B2. It's easy for me to relax.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B3. If something can go wrong for me, it will.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B4. I'm always optimistic about my future	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B5. I enjoy my friends a lot.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B6. It's important for me to keep busy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B7. I hardly ever expect things to go my way.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B8. I don't get upset too easily.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B9. I rarely count on good things happening to me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B10. Overall, I expect more good things to happen to me than bad.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 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?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
C2 Do you have any trouble taking a <u>long</u> walk?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

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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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

C4	Do you need to stay in bed or a chair during the day?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C5	Do you need help with eating, dressing, washing yourself or using the toilet?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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During the past week:		Not at all	A little	Quite a bit	Very Much
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C6	Were you limited in doing either your work or other daily activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C7	Were you limited in pursuing your hobbies or other leisure time activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C8	Were you short of breath?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C9	Have you had pain?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C10	Did you need to rest?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C11	Have you had trouble sleeping?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C12	Have you felt weak?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C13	Have you lacked appetite?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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During the past week:		Not at all	A little	Quite a bit	Very Much
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C14	Have you felt nauseated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C15	Have you vomited?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C16	Have you been constipated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C17	Have you had diarrhoea?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
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C18	Were you tired?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C21	Did you feel tense?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C22	Did you worry?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C23	Did you feel irritable?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C24	Did you feel depressed?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C25	Have you had difficulty remembering things?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C26	Has your physical condition or medical treatment interfered with your <u>family</u> life?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C27	Has your physical condition or medical treatment interfered with your <u>social</u> activities?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄				
C28	Has your physical condition or medical treatment interfered caused you financial difficulties?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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 <u>health</u> during the past week?								
	Very poor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Excellent
C30	How would you rate your overall <u>quality of life</u> during the past week?								
	Very poor	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Excellent

Study number: T headandneck
5000**Specific Aspects of Your Health**

We are interested in some things about you and specific aspects of 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.

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

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

Study number: T headandneck
5000**During the past week:**

		Yes	No
D31	Have you used painkillers?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D32	Have you taken any nutritional supplements (excluding vitamins)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D33	Have you used a feeding tube?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D34	Have you lost weight?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
D35	Have you gained weight?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

Your Feelings

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

E1 I feel tense or 'wound up':

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

E2 I still enjoy the things I used to enjoy:

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

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

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

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

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

E5 Worrying thoughts go through my mind:

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

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E6 I feel cheerful:

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

E7 I can sit at ease and feel relaxed:

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

E8 I feel as if I am slowed down:

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

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

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

E10 I have lost interest in my appearance:

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

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

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

E12 I look forward with enjoyment to things:

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

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5000**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

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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 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

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*

*Please tick
as appropriate
NA – not applicable

If yes, please indicate

H1. Paid for any kind of medication?
(e.g. conventional, alternative)

☐ ₁ ☐ ₂ ☐ ₃

Type(s) of medication

_____a

Approximate amount

£ _____b

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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

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?

☐₁ ☐₂ ☐₃

For you

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?

☐₁ ☐₂ ☐₃

For your family

Number of weeks or months (delete as appropriate)

_____a

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

☐₁ ☐₂ ☐₃

For you

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?

☐₁ ☐₂ ☐₃

For your family

Approximate amount of gross income that has been lost in total

£ _____b

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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.

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.

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- ☐ 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.
- ☐ 4 I cannot work due to problems with my shoulder.

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.

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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.

- | | | |
|--|--|--|
| <input type="checkbox"/> ₁ Pain | <input type="checkbox"/> ₅ Swallowing | <input type="checkbox"/> ₉ Taste |
| <input type="checkbox"/> ₂ Appearance | <input type="checkbox"/> ₆ Chewing | <input type="checkbox"/> ₁₀ Saliva |
| <input type="checkbox"/> ₃ Activity | <input type="checkbox"/> ₇ Speech | <input type="checkbox"/> ₁₁ Mood |
| <input type="checkbox"/> ₄ Recreation | <input type="checkbox"/> ₈ Shoulder | <input type="checkbox"/> 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

I15. In general, would you say your *health-related quality of life* during the past 7 days 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* during the past 7 days. (Tick one box: ☒)

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- ☐ 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 difficulty	Quite a bit of difficulty	Very much difficulty
J1	Have you had any difficulty maintaining your independence?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J2	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J3	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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J4	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J5	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J6	Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J7	Have you had any financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J8	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the past month:		No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
J9	Have you had any difficulty concerning your work? (or education if you are a student)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J11	Have you had any difficulty communicating with those closest to you? (e.g. partner, children, parents)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J12	Have you had difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J13	Have you had any difficulty concerning sexual matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J14	Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J15	Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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J16	Have you felt isolated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J17	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J18	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J19	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J20	Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J21	Have you had any difficulty with any other area of your everyday life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.

Study number: T headandneck
5000**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

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

Study number: T headandneck
5000Extremely ☐ ₅**K7B Other people mis-judge me because of the appearance of my head/neck:**Almost always ☐ ₁Often ☐ ₂Sometimes ☐ ₃Never/almost never ☐ ₄N/A ☐ ₅**K8B How feminine/masculine do you feel?**Not at all ☐ ₁Slightly ☐ ₂Moderately ☐ ₃Extremely ☐ ₄**K19B How distressed do you get when going to social events?**N/A ☐ ₁Not at all ☐ ₂Moderately ☐ ₃A fair amount ☐ ₄Extremely ☐ ₅**K20B How normal do you feel?**Not at all ☐ ₁Slightly ☐ ₂Moderately ☐ ₃Extremely ☐ ₄**K21B At present my self-consciousness has an adverse effect on my sex life:**Almost always ☐ ₁Often ☐ ₂

Study number: **T** headandneck
5000

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

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

Study number: T



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				Moderately			Extremely
noticeable				Noticeable			Noticeable
1	2	3	4	5	6	7	
<input type="text"/> ₁	<input type="text"/> ₂	<input type="text"/> ₃	<input type="text"/> ₄	<input type="text"/> ₅	<input type="text"/> ₆	<input type="text"/> ₇	

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

Not at all					Very much
1	2	3	4	5	
<input type="text"/> ₁	<input type="text"/> ₂	<input type="text"/> ₃	<input type="text"/> ₄	<input type="text"/> ₅	

K6C How much does this bother you?

Not at all				Very much so
1	2	3	4	5
<input type="text"/> ₁	<input type="text"/> ₂	<input type="text"/> ₃	<input type="text"/> ₄	<input type="text"/> ₅

Thank you for
completing the questionnaire

B.4.3 Supplementary Questionnaire Pack (Bristol only)

Study number: T

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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.

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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.

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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.

- | | | |
|--|--|--|
| <input type="checkbox"/> ₁ Pain | <input type="checkbox"/> ₅ Swallowing | <input type="checkbox"/> ₉ Taste |
| <input type="checkbox"/> ₂ Appearance | <input type="checkbox"/> ₆ Chewing | <input type="checkbox"/> ₁₀ Saliva |
| <input type="checkbox"/> ₃ Activity | <input type="checkbox"/> ₇ Speech | <input type="checkbox"/> ₁₁ Mood |
| <input type="checkbox"/> ₄ Recreation | <input type="checkbox"/> ₈ Shoulder | <input type="checkbox"/> 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

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5000**I15. In general, would you say your *health-related quality of life* during the past 7 days 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* during the past 7 days. (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? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |
| J2 | Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

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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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J4	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J5	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J6	Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J7	Have you had any financial difficulties?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J8	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J9	Have you had any difficulty concerning your work? (or education if you are a student)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J11	Have you had any difficulty communicating with those closest to you? (e.g. partner, children, parents)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J12	Have you had difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J13	Have you had any difficulty concerning sexual matters?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J14	Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J15	Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J16	Have you felt isolated?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J17	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J18	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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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)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J20	Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
J21	Have you had any difficulty with any other area of your everyday life?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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

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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

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noticeableModerately
noticeableExtremely
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

B.4.4 Toxicity Scale

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Head and Neck Radiotherapy Questionnaire (LATE TOXICITY)

Your Symptoms

Please answer the questions as to how you've 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
- Others ☐ 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

Medication	How often
_____	_____
_____	_____

L5 Does the pain or painkillers interfere with daily self care activities (see bottom of page)*?

- No ☐ ₁
- Yes ☐ ₂

*Eg. bathing, getting about indoors, dressing, getting In / out of bed

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The next few questions are about your mouth or eating:**L6 Have you lost your appetite'?**No ☐ ₁Yes ☐ ₂

L7 Have you had difficulties in swallowing?No ☐ ₁Yes ☐ ₂

L8 Have you any difficulty opening your mouth?No ☐ ₁Yes ☐ ₂

L9 Do you have any alteration in your taste?No ☐ ₁Yes ☐ ₂

L10 If Yes, have you had any loss of taste and / or do you find taste unpleasant?No ☐ ₁Yes ☐ ₂

L11 Have you had a dry mouth?No ☐ ₁Yes ☐ ₂

L12 Have you had any changes to your saliva?None ☐ ₁Yes, it's slightly thickened ☐ ₂Yes, it's ropery, thick and sticky ☐ ₃

L13 If Yes, has it affected your taste?No ☐ ₁Yes, slightly ☐ ₂Yes, markedly ☐ ₃

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L14 If you have saliva changes, how has it affected your daily self care activities*?
Not at all ☐ ₁Interferes with self care activities ☐ ₂Unable to self care ☐ ₃

*Eg bathing, getting about Indoors dressing, getting in / out of bed

L15 Has your diet been significantly affected?
Normal regular diet ☐ ₁Yes, but can manage solid food ☐ ₂Yes, mostly soft or liquidised food ☐ ₃Cannot eat I 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 ☐ ₁Dry mouth ☐ ₂Difficulty opening mouth ☐ ₃Loss of appetite ☐ ₄Altered taste ☐ ₅Change in saliva ☐ ₆Others ☐ ₇ Please state: _____

L17 If you are on supplementary nutritional drinks, why are you requiring them? (tick all that apply)
Not on supplementary drinks ☐ ₁Difficulty in swallowing ☐ ₂Weight loss ☐ ₃Loss of appetite ☐ ₄Altered taste ☐ ₅Others ☐ ₆ Please state: _____

The next few questions are about your skin in the area treated with radiotherapy:
L18 Have you any visible roughness or flaking of your skin
No ☐ ₁Yes ☐ ₂

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L19 If Yes, how obvious is it?Only close-up ☐ ₁Easily apparent ☐ ₂**L20 If Yes, does this affect your appearance?**No ☐ ₁Yes ☐ ₂Would like surgery if feasible ☐ ₃**L21 Have you any thickening or hardening of your skin (skin fibrosis)?**No ☐ ₁Yes ☐ ₂**L22 If Yes, how severe is the skin thickening / hardening?**Mild ☐ ₁Marked ☐ ₂Interferes with self care activities ☐ ₃**L23 Have you any skin itchiness?**No ☐ ₁Mild and localised ☐ ₂Intense or widespread ☐ ₃Interferes with self care activities ☐ ₄**L24 Do you have any puffiness in your head and neck?**No ☐ ₁Yes ☐ ₂**L25 If Yes, has it interfered with any function (eg turning your head or opening mouth) compared with before radiotherapy?**No ☐ ₁Yes ☐ ₂

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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

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

- | | |
|----------------|---------------------------------------|
| No | <input type="checkbox"/> ₁ |
| Yes, rarely | <input type="checkbox"/> ₂ |
| Yes, sometimes | <input type="checkbox"/> ₃ |
| Yes, often | <input type="checkbox"/> ₄ |

L33 If Yes, how has it affected your daily self care activities* ?

- | | |
|--------------------------------------|---------------------------------------|
| Not at all | <input type="checkbox"/> ₁ |
| Interferes with self care activities | <input type="checkbox"/> ₂ |
| Cannot self care | <input type="checkbox"/> ₃ |

*Eg bathing, getting about indoors dressing, getting in / out of bed

Thank you for
completing the questionnaire

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