headandneck 5000

Tier 1 Data Manual
v3.0

www.headandneck5000.org.uk

Date of data extraction from H&N5000 database – 01/10/2023

This Data Manual was produced on – 09/05/2024

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Review date	Version number	Version date	Reason for change	Author	Date Authorised by HN5000 Executive
N/A	v1.0		Original	S. Toms	22/05/2024

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1.   Introduction

This document is the Tier 1 Data Manual for the Head and Neck 5000 study (H&N5000), version 3.0.

The Head and Neck 5000 study is a prospective clinical cohort involving approximately 5,000 people with head and neck cancer. The primary aim was to evaluate the outcome of centralisation in head and neck cancer services, but preliminary analysis suggests little variation in outcomes between centres.

This manual covers various aspects, including recruitment criteria, data collection methods, questionnaire sections, available variables, and application procedures for accessing the data.

Data were collected from clinical notes and participants at four timepoints: baseline, 4 months, 12 months, and 36+ months. The questionnaire sections cover various topics such as demographics, health behaviours, general health, specific health aspects, feelings, diet, thoughts around cancer recurrence, personal costs, quality of life, difficulties in life, appearance, late toxicity, and sexual history.

The available variables include demographic information, baseline health behaviours, data from the Baseline Data Capture Form, mortality data, and questionnaire variables covering different sections. Each variable has a specific name and definition.

This manual also outlines the application process for researchers to access the data, which involves submitting a Head and Neck 5000 Resource Research Proposal Form, variable request, and undergoing approval from the Head and Neck 5000 Executive Group.

This document serves as a comprehensive guide for researchers intending to use data from the Head and Neck 5000 study for various research purposes related to head and neck cancer.

All 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 Head and Neck 5000 datasets.

1.1 Background

Full details of the H&N5000 study can be found at 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 coordinated resource for aetiologic, translational and prognostic research. The first recruitment site opened on 5th April 2011, with the first participant being consented to the study on the 7th April 2011. Recruitment was completed on 31st December 2014.

1.2 Study Aims 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:

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

We have described the centralised multi-disciplinary service in the UK. However, preliminary analysis suggests there is little variation in outcome between centres, so we are unlikely to be able to evaluate the impact of centralisation on outcome. We have established an important bio-medical resource that is being widely used and that making important contributions to aetiologic and prognostic research.

2.   Recruitment

Participants were recruited from 76 study sites across England, Scotland, and Wales. Every person with a presumed new diagnosis of head and neck cancer seen or discussed at the Multidisciplinary Team (MDT) meeting or clinic was eligible for inclusion into the study. This included those enrolled in other observational studies or trials.

Patients with an unknown primary, and those without a histological diagnosis, were eligible if the MDT decision was that the primary is likely to be a head and neck cancer and the patient is aware of the clinical decision.

The following exclusion criteria were applied : -

- People who were considered to meet the criteria for mental incapacity or vulnerability set out in the mental capacity/vulnerable adult act.
- People who did not have cancer of the head and neck.
- People who had a recurrence of their cancer of the head and neck rather than a new diagnosis.
- People with lymphoma.
- People with skin cancer.
- People with a secondary head and neck tumour.
- People aged under 16.
- Patients who have already commenced their cancer treatment (with the exception of those whose treatment is also their diagnostic procedure)
- Carcinoma in Situ where there is no evidence of invasion (these patients were only eligible if a clinical diagnosis of cancer had been made by the MDT)

2.1 Recruitment Heat Map

This map shows the distribution of participants recruited across the UK, by their postcode locations.
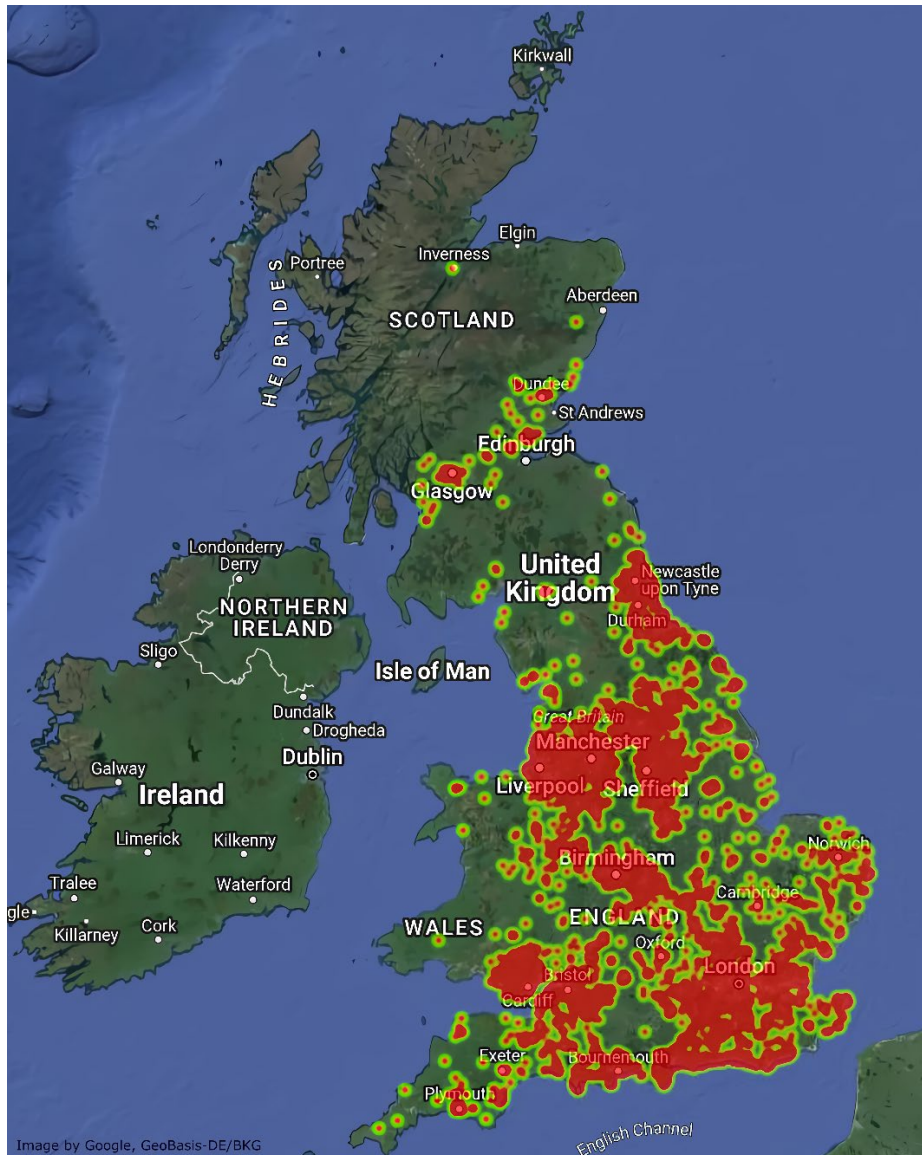
3.   Application Process

- Applicants are to familiarise themselves with the latest documentation from the H&N5000 website at www.headandneck5000.org.uk.

- Applicant completes the HN5000 Project application webform https://forms.office.com/e/0RSS2n4BLT

- The application will be considered by the HN5000 Executive Group within 28 days. If approved, a member of the Executive Group will be assigned to your project.

- If approved you will receive a confirmation email from the HN5000 Executive Group, this email will also include a link to the variable request form, publication checklist and sample DMTA.

- Using this document for reference, complete the Variable Request form.

- Once submitted your request will be processed and data released when contracts, ethics and funding documentation is complete.

- You will be sent a password protected encrypted zip file data pack, containing a copy of your variable request, a csv and a txt file containing your data. Your data will have been assigned project specific Study ID Numbers, so will not be linkable with any other projects.

- Please note, we are unable to provide any explicit dates in our datasets, you will instead be provided with a count of days from consent to the date requested.

4. Data Collection

Data were collected from clinical notes and participants at four timepoints.

4.1 Data collection timeline

	Baseline	4 months	12 months	36+ months
Clinical Data				
Clinical Samples	✓			
Clinical data from notes	✓	✓	✓	✓
Questionnaires				
About You	✓	✓	✓	✓
Your Outlook	✓	✓	✓	✓
Your General Health	✓	✓	✓	✓
Specific Aspects of Your Health	✓	✓	✓	✓
Your Medical History				✓
Your Feelings	✓	✓	✓	✓
Eating and Your Diet	✓	✓	✓	✓
Thoughts Around Cancer Recurrence		✓	✓	✓
Your Personal Costs		✓	✓	✓
Your Quality of Life[1]	✓	✓	✓	
Difficulties in Your Life[1]	✓	✓	✓	
Your Dental Health				✓
Sexual History	✓			
Your Appearance[1]	✓	✓	✓	
Your Symptoms[2]			✓	✓

[1] These questions were administered to participants from one site only.

[2] For people that received radiotherapy only.

4.2 Questionnaire Sections

In this section we describe the questions used in the Head and Neck 5000 (H&N5000) study. Questionnaires were given out at baseline (consent) and sent out at 4 and 12 months after consent during the original study. A further questionnaire was sent out 3 – 5 years after consent in the Follow up study. We divided the content of the questionnaires into sections that are made up of one or more groups and have summarised these in the table below. For each group of questions, we have included what the questions measure, validation of the questions and when used in Head and Neck 5000.

Section	Title	Research Topic	Ref
A	About You	Demographics: Date of birth, height, weight, gender, postcode, ethnicity, marital status, and education **(A3-A7)**	These are new questions designed for this study.

		Smoking and alcohol use **(A8-12 and A13-16)**	These questions were originally developed for use in the CLEAR study (Sitas et al., 2015) and The Million Women study (The Million Women Study, 1999). The CLEAR study recruited residents of New South Wales, Australia ≥18 years old, with a first incident cancer. The Million Women Study is a national UK study of women's health, involving more than one million UK women aged 50 and over.
		Marijuana use **(A12A-A12C)**	These questions have not been formally validated. The questions were developed for use in this questionnaire. The marijuana terms used in these questions were selected based on a previously published questionnaire on substance abuse, which was used as part of the European School Survey Project on Alcohol and Other Drugs (ESPAD, 2016).
		Working and income **(A17-A23)**	These questions were adapted from West of Scotland Twenty-07 cohort Study (Benzeval et al., 2009) and the Alcohol-Related Cancers And Genetic-Susceptibility (ARCAGE) European multicentre head and neck case control study (Lagiou et al., 2009).
		Health Status - WHO / Eastern Cooperative Oncology Group (ECOG) performance status **(A24)**	The WHO/ECOG performance status has been shown to be reliable in studies which have tested its inter-observer variability. Both patient and oncologist assessed scores have been shown to reflect survival duration as well as disease stage with oncologist assessed scores being only marginally more predictive of survival (Blagden et al., 2003).
		Health Status EQ-5D- 5L **(A25-A26)**	EQ-5D health states can be converted into to a single summary index by applying a formula which attaches weights to each of the levels in each dimension. Instructions on how to code the EQ-5D-5L can be found on the EuroQol website: (EuroQol, 2019).
B	Your Outlook	Life orientation test revised **(B1-10)**	The LOT-R has been used extensively in research and has proven useful in predicting psychological well-being, physical health and recovery after severe illness or surgery (Glaesmer et al., 2012; Scheier et al., 1994).
C	Your General Health	Quality of Life – The European Organisation for the Research and Treatment of Cancer (EORTC) QLQ-30 **(C1-C30)**	The EORTC-QLQ-C30 was first validated in a cross-cultural sample of lung cancer patients, conducted across 13 countries (Aaronson *et al.*, 1993). It has since been used in a wide range of cancer clinical trials, by a large number of research groups.
D	Specific Aspects of Your Health	EORTC Head and neck specific quality of life QLQ - H&N35 **(D1-D35)**	The EORTC QLQ-H&N35, in conjunction with the QLQ-C30, was tested and validated in a large and diverse sample (n = 622) of people from twelve different countries including the UK who had either been newly diagnosed with HNC, had recurrent HNC or who had been disease-free for 1-3 years after treatment (Bjordal et al., 1993). The instrument was found to be well accepted, had a high level of construct validity, and was responsive to differences between disease status, site, and patients with different performance status.

		Patient reported outcome Charlson Co-Morbidity Index (PRO-CCI) **(D36-54)** These questions were only used in the 3 – 5 year follow up questionnaire.	The original PRO-CCI was administered to 882 people with head and neck cancer (Habbous et al., 2013). Whilst this patient-reported version correlated well with the standard (medical record-abstracted) CCI for comorbidities including diabetes and prior cancer, connective tissue disease (CTD) and chronic obstructive pulmonary disease (COPD) showed marked disagreement. Discrepancies were thought to be a result of people reporting various non-rheumatological diseases or symptoms of CTD (e.g. osteoarthritis or aches and pains in the bones and joints). As a result, a modified PRO-CCI questionnaire was developed which aimed to provide more accurate reporting for CTD. This modified version was validated in an additional cohort of people with head and neck cancer, lung, or oesophageal cancer (n=102). The modified PRO-CCI demonstrated high compliance, a good level of agreement with the standard CCI and was a good predictor of survival cancer (Habbous et al., 2013).
		History of cervical cancer **(D55-D56)** These questions were only used in the 3 – 5 year follow up questionnaire.	These questions were developed for this study and have not been used elsewhere.
		History of tonsillectomy **(D57-D58)** These questions were only used in the 3 – 5 year follow up questionnaire.	These questions were developed for this study and have not been used elsewhere.
E	Your Feelings	Hospital Anxiety and Depression Scale **(E1-E14)**	Whilst HADS was developed as a screening instrument for use in hospital outpatient departments, it has subsequently been validated for use within primary care settings and within the general population (McDowell, 2006; Snaith, 2003). Its use has been supported in two major reviews (Herrmann, 1997; Bjelland et al., 2002). Studies have used the HADS to examine psychological distress in people with head and neck cancer, worldwide and in the UK specifically. For a comprehensive overview of these, please see Joseph et al., 2013.
F	Your Diet	Fruit, vegetable, and fried food consumption **(F1-F3)**	These questions have been modified from the semi-quantitative food frequency questionnaire (FFQ). The FFQ questionnaire was validated in a large prospective study of 173 female registered nurses aged 34-59 years, residing in the Boston area from 1980 to 1981 (Willett et al., 1985). The authors concluded that the self-administered dietary questionnaire could provide useful information about individual nutrient intakes over a one-year period.

		Eating habits **(F4-F10)** These questions were only used in the 3 – 5 year follow up questionnaire.	These questions were developed for this study and have not been used elsewhere.
		Antacid use **(F11-F14)** These questions were only used in the 3 – 5 year follow up questionnaire.	These questions were developed for this study and have not been used elsewhere.
		Feeding tubes **(F15-F20)** These questions were only used in the 3 – 5 year follow up questionnaire.	These questions were developed for this study and have not been used elsewhere.
G	You and Cancer	Fear of recurrence **(G1-G4)**	The four items used are part of the seven-item scale used in (Rogers et al., 2016)
H	Your Personal Costs	Cost of cancer over the last year **(H1-H12)**	These questions were developed for this study by Dr. Melissa Ke and have not been used elsewhere.
I	Your Quality of Life	The revised University of Washington QoL questionnaire **(I1–I17)** Data only collected at three sites	The questionnaire is widely used and has been validated in studies by Hassan and Weymuller (1993) and the revised version of the questionnaire by Rogers et al (2002).
J	Difficulties in Your Life	The Social Difficulties Inventory **(J1 – J21)** Data only collected at three sites	The Social Difficulties Inventory is a validated questionnaire developed for assessing social difficulties in cancer patients (Wright P et al. 2005)
K	Your Appearance	The Derriford Appearance Scale **(K selected numbers)** Data only collected at three sites	The DAS24 is widely applicable, psychometrically robust and discriminates well between patient groups, between clinical and non-clinical populations (Carr and Moss 2005).
L	Late Toxicity	Late Radiotoxicity questionnaire **(L1-L27)**	These questions have been developed as part of the RAPPER study (Radiogenomics: Assessment of Polymorphisms for Predicting the Effects of Radiotherapy). The main objective of the RAPPER study is to understand why some patients who receive radiotherapy are more likely to experience side effects than others. The study aimed to recruit >6000 people with different cancer types, including breast; prostate; gynaecological; lung; and head and neck cancers. Questionnaires were designed specifically for each cancer group. We have used the questions outlined in the RAPPER head and neck questionnaire.

M	Sexual History	Sexual history questionnaire **(M1-M9)**	The questions are from a questionnaire designed by Sonia Duffy at the University of Michigan.
T	Your Dental Health	Teeth and dental care **(T1-T4)** These questions were only used in the 3 – 5 year follow up questionnaire.	Question T1 is a revised version of the Scottish Health Survey (SHS) dental module question 1 (ScotCen Social Research et al., 2016). People are able to provide reasonably reliable self-reported data concerning the number of natural teeth present (Axelsson and Helgadottir, 1995; Heløe LA 1972). Questions T2, T3 and T4 are also amended SHS dental questions.

5. Available Variables

5.1 Core Variable Descriptions

These core variables are provided to every applicant; therefore, they do not need to be requested separately.

Variable description		Variable name
General		
1.	Project specific anonymised ID	CollabID
Demographics		
2.	Sex	hn1_dv_sex
3.	Age at consent	hn1_dv_age_at_cnsnt
4.	Height	hn1_dv_ay_height_cm
5.	Weight at baseline	hn1_dv_ay_weight_kg
6.	Ethnicity (site reported)	hn1_dv_ethnicity
7.	Marital status	hn1_ay_a5_crrntmaritalstat
8.	Highest educational level obtained	hn1_ay_a7a_educationlvl
9.	Total household income (at baseline)	hn1_dv_ay_hhold_income
10.	Index of Multiple Deprivation	hn1_imd10quint
Baseline health behaviour		
11.	Baseline smoker status	hn1_ay_a8_tobac
12.	Alcohol consumption	
a.	Days/week	hn1_dv_ay_drink_days
b.	Units/week	hn1_dv_ay_units_per_wk
Baseline Data Capture Form		
13.	Grouped ICD code	hn1_dv_icd_group_conf
14.	Pre-diagnosis staging (simplified)	hn1_dv_tnm_stage_best
15.	Cancer plan intent	hn1_dcf_b1a_planintent_1
16.	Co-morbidity (at diagnosis)	hn1_dcf_b4_comorbindex
17.	Planned treatment	hn1_dv_tx_planned_group
17.	Received treatment	hn2_dv_tx_actual_group
18.	Tumour HPV status - p16	hn1_dcf_b9a_hpvstatus
Mortality data		
19.	Was participant alive at censoring date?	hn1_dv_vital_status
20.	Days from consent to censoring or death	hn1_dv_days_frm_cnsnt_to_censdth

5.2 Questionnaire Variable Descriptions

5.2.1 Section A - About You

Variable Name	Definition	New Derived Variable Name	Timepoints			
			HN1	HN2	HN3	HN4
ay_a1_Date	Date of questionnaire completion.	dv_days_frm_cnsnt_to_q				
ay_a2_DateOfBirth	Date of birth	dv_age_at_cnsnt				
ay_a3_Height	Height	dv_ay_height_cm				
ay_a4_Weight	Weight	dv_ay_weight_kg				
ay_a4a_Weight6MnthsAgo	Weight 6 months ago	dv_ay_weight_6mnths_ago_kg				
ay_a4b_TriedLsngWght	Have you tried to lose weight over the last six months?					
ay_a5_CrrntMaritalStat	Are you currently?					
ay_a6_EducationYrs	How many years of full-time education did you complete?					
ay_a7a_EducationLvl	What is the highest educational level you obtained?					
ay_a7b_EducationLvlOth	What is the highest educational level you obtained? Other specified					
ay_a8_Tobac	Are you a current user of tobacco or, have you recently quit using tobacco or never used tobacco?					
ay_a8a_TobacDuringTx	Did you use tobacco during the time that you received treatment for your head and neck cancer?					
ay_a8b_TobacHowLngStop	If you are a former user of tobacco, when did you stop using tobacco?					
ay_a8c_TobacTryQuitDiag	If you are a current user of tobacco, did you try to quit following your diagnosis with head and neck cancer?					
ay_a8d1_TobacQuitYears	If you tried to quit, how long did you stop using tobacco for : Years					
ay_a8d2_TobacQuitMonths	If you tried to quit, how long did you stop using tobacco for : Months					
ay_a8d3_TobacQuitWeeks	If you tried to quit, how long did you stop using tobacco for : Weeks					
ay_a9_TobacHowLngStopYrs	If you are a former tobacco user, how long ago did you stop using tobacco? : Years					
ay_a10_TobacUseAgeStart	At what age did you begin to use tobacco products?					
ay_a11a_TobacUsageCigsDay	Number of cigarettes per day?					
ay_a11b_TobacUsageRollDay	Number of hand rolled cigarettes per day?					
ay_a11c_TobacUsagePipeDay	Number of pipes or cigars per day?					
ay_a11d_TobacUsageSmklssDay	Number of smokeless tobacco per day?					
dv_ay_pack_years	*Refer to derived Section A variables table below*					
ay_a12_Tobacbrand	What brand of cigarettes / tobacco do you normally smoke?					
ay_a12a_MarijUsage	How many times (if at all) have you used marijuana or hashish (cannabis) in your life?					

Variable	Question	Derived variable
ay_a12b1_MarijLstUsdDays	How long ago did you last use marijuana or hashish (cannabis)? : Days	
ay_a12b2_MarijLstUsdMnths	How long ago did you last use marijuana or hashish (cannabis)? : Months	
ay_a12b3_MarijLstUsdYrs	How long ago did you last use marijuana or hashish (cannabis)? : Weeks	
ay_a12c_MarijCrrntUser	If you are a current user of marijuana or hashish (cannabis), do you use it for:	
ay_a13a_DrnkDays	In a typical week how many days do you drink alcohol? Please enter the	dv_ay_drink_days
ay_a13b_DrnkDaysNone	number of days in the box. If none, tick the box and go to question A17	dv_ay_drink_ever
ay_a14_DrnkBfrIllWeek	Just before you became ill, how many alcoholic drinks did you have each week?	
ay_a15a_DrnkWineWeek	About how many bottles of wine do you drink on average each week?	
ay_a15b_DrnkSpiritsWeek	About how many bottles of spirits do you drink on average each week?	
ay_a15c_DrnkPintsWeek	About how many pints of beer do you drink on average each week?	
dv_ay_units_per_wk	***Refer to derived variables table***	
ay_a16_DrnkBrand	What brand of alcohol do you normally drink?	
ay_a17_WrkingCurrnt	Are you currently working?	
ay_a17a_WrkOccupation	If you are currently working, what is your occupation?	
ay_a18_WrkingCurrntHrs	If you are currently working, how many hours per week do you work?	
ay_a18a_WrkNoLonger	Why do you no longer work?	
ay_a18a1_WrkNoLongerOth	Why do you no longer work? Other specified	
ay_a19_WrkingOccupLongest	What was the occupation/job which you had for the longest time in your life?	
ay_a20_WrkingEvrUnemployed	Have you ever been unemployed?	
ay_a21_IncmHholdTotal	What is your total household income from all sources before tax & other deductions?	dv_ay_hhold_income
ay_a22_IncmHholdBenfts	What proportion of your household income (including your own) would you say comes from benefits?	
ay_a22a_IncmAppldWelfare	If you have applied for welfare benefits, did you have any support to do this?	
ay_a23a_CncrnsNone	At present do you have any concerns about any of the following aspects of living with or after cancer? : No	
ay_a23b_CncrnsFinancial	At present do you have any concerns about any of the following aspects of living with or after cancer? : Financial concerns	
ay_a23c_CncrnsStyngWrkcllg	At present do you have any concerns about any of the following aspects of living with or after cancer? : Staying in work/college	
ay_a23d_CncrnsCostAppntmnts	At present do you have any concerns about any of the following aspects of living with or after cancer? : Cost of attending appointments	
ay_a23e_CncrnsTimeoff	At present do you have any concerns about any of the following aspects of living with or after cancer? : Taking time off work/college	

Variable	Definition				
ay_a23f_CncrnsRtrnWrkcllg	At present do you have any concerns about any of the following aspects of living with or after cancer? : Returning to work/college				
ay_a24_PhysAbility	Please tick the box that describes best what you can do				
ay_a25a_Eq5dMobility	EQ5D : Mobility				
ay_a25b_Eq5dSelfcare	EQ5D : Self care				
ay_a25c_Eq5dUsualActiv	EQ5D : Usual activities				
ay_a25d_Eq5dPain	EQ5D : Pain discomfort				
ay_a25e_Eq5dAnxiety	EQ5D : Anxiety/depression				
ay_a26_Eq5dHlthScale	EQ5D : We would like to know how good or bad your health is TODAY. This scale is numbered from 0 – 100. 100 means the best health you can imagine. 0 means the worst health you can imagine				

5.2.2 Section B – Your Outlook

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
yo_b1_UncertainTimes	In uncertain times, I usually expect the best.				
yo_b2_EasyForMeToRelax	It's easy for me to relax.				
yo_b3_GoWrong	If something can go wrong for me, it will.				
yo_b4_OptimisticFuture	I'm always optimistic about my future.				
yo_b5_EnjoyFriends	I enjoy my friends a lot.				
yo_b6_ImportantKeepBusy	It's important for me to keep busy.				
yo_b7_DontExpctThngsMyWy	I hardly ever expect things to go my way.				
yo_b8_DoNotGetUpsetEasily	I don't get upset too easily.				
yo_b9_RarelyGoodThings	I rarely count on good things happening to me.				
yo_b10_ExpectMoreGood	Overall, I expect more good things to happen to me than bad.				

5.2.3   Section C – Your General Health

Variable Name	Definition	HN1	HN2	HN3	HN4
		Timepoints			
ygh_c1_TroubleStrenActv	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?				
ygh_c2_TroubleLongWalk	Do you have any trouble taking a long walk?				
ygh_c3_TroubleShortWalk	Do you have any trouble taking a short walk outside of the house?				
ygh_c4_NeedBedChairDay	Do you need to stay in bed or a chair during the day?				
ygh_c5_NeedHelpEatingEtc	Do you need help with eating, dressing, washing yourself or using the toilet?				
ygh_c6_LimitedDailyActv	During the past week : Were you limited in doing either your work or other daily activities?				
ygh_c7_LimitedHobbies	During the past week : Were you limited in pursuing your hobbies or other leisure time activities?				
ygh_c8_ShortOfBreath	During the past week : Were you short of breath?				
ygh_c9_HadPain	During the past week : Have you had pain?				
ygh_c10_NeedToRest	During the past week : Did you need to rest?				
ygh_c11_TroubleSleeping	During the past week : Have you had trouble sleeping?				
ygh_c12_FeltWeak	During the past week : Have you felt weak?				
ygh_c13_LackedAppetite	During the past week : Have you lacked appetite?				
ygh_c14_FeltNauseated	During the past week : Have you felt nauseated?				
ygh_c15_Vomited	During the past week : Have you vomited?				
ygh_c16_Constipated	During the past week : Have you been constipated?				
ygh_c17_Diarrhoea	During the past week : Have you had diarrhoea?				
ygh_c18_Tired	During the past week : Were you tired?				
ygh_c19_PainDailyActv	During the past week : Did pain interfere with your daily activities?				
ygh_c20_DiffCncntrtng	During the past week : Have you had difficulty in concentrating on things, like reading a newspaper or watching television?				
ygh_c21_FeelTense	During the past week : Did you feel tense?				
ygh_c22_Worry	During the past week : Did you worry?				
ygh_c23_Irritable	During the past week : Did you feel irritable?				
ygh_c24_Depressed	During the past week : Did you feel depressed?				
ygh_c25_DiffRemembering	During the past week : Have you had difficulty remembering things?				
ygh_c26_FamilyLife	During the past week : Has your physical condition or medical treatment interfered with your family life?				
ygh_c27_SocialActv	During the past week : Has your physical condition or medical treatment interfered with your social activities?				
ygh_c28_FinancialDiff	During the past week : Has your physical condition or medical treatment caused you financial difficulties?				
ygh_c29_RateHlthLstWeek	How would you rate your overall health during the past week?				
ygh_c30_RateQlLfeLstWeek	How would you rate your overall quality of life during the past week?				

5.2.4 Section D – Specific Aspects of Your Health

Variable Name	Definition	New Derived Variable Name	Timepoints			
			HN1	HN2	HN3	HN4
sayh_d1_PainMouth	During the past week : Have you had pain in your mouth?					
sayh_d2_PainJaw	During the past week : Have you had pain in your jaw?					
sayh_d3_SorenessMouth	During the past week : Have you had soreness in your mouth?					
sayh_d4_PainfulThroat	During the past week : Have you had a painful throat?					
sayh_d5_SwallowingLiquid	During the past week : Have you had problems swallowing liquids?					
sayh_d6_SwallowingPuree	During the past week : Have you had problems swallowing pureed food?					
sayh_d7_SwallowingSolids	During the past week : Have you had problems swallowing solid food?					
sayh_d8_ChokedSwallowing	During the past week : Have you choked when swallowing?					
sayh_d9_ProbTeeth	During the past week : Have you had problems with your teeth?					
sayh_d10_ProbsOpenMouth	During the past week : Have you had problems opening your mouth wide?					
sayh_d11_DryMouth	During the past week : Have you had a dry mouth?					
sayh_d12_StickySaliva	During the past week : Have you had sticky saliva?					
sayh_d13_SenseSmell	During the past week : Have you had problems with your sense of smell?					
sayh_d14_SenseTaste	During the past week : Have you had problems with your sense of taste?					
sayh_d15_Coughed	During the past week : Have you coughed?					
sayh_d16_Hoarse	During the past week : Have you been hoarse?					
sayh_d17_FeltIll	During the past week : Have you felt ill?					
sayh_d18_Appearance	During the past week : Has your appearance bothered you?					
sayh_d19_TrbEating	During the past week : Have you had trouble eating?					
sayh_d20_TrbEatingFrntFam	During the past week : Have you had trouble eating in front of your family?					
sayh_d21_TrbEatingFrntOth	During the past week : Have you had trouble eating in front of other people?					
sayh_d22_TrbEnjoyngMeals	During the past week : Have you had trouble enjoying your meals?					
sayh_d23_TrbTlkngPeople	During the past week : Have you had trouble talking to other people?					
sayh_d24_TrbTlkngPhone	During the past week : Have you had trouble talking on the telephone?					
sayh_d25_TrbSocialFamily	During the past week : Have you had trouble having social contact with your family?					
sayh_d26_TrbSocialFrnds	During the past week : Have you had trouble having social contact with friends?					
sayh_d27_TrbGngOutPublic	During the past week : Have you had trouble going out in public?					
sayh_d28_Physical	During the past week : Have you had trouble having physical contact with family or friends?					

Variable	Question					
sayh_d29_LessInterestSex	During the past week : Have you felt less interest in sex?		🟩			
sayh_d30_LessSexEnjoymnt	During the past week : Have you felt less sexual enjoyment?		🟩			
sayh_d31_UsedPainkillers	During the past week : Have you used painkillers?		🟩			
sayh_d32_NutritinlSuppl	During the past week : Have you taken any nutritional supplements (excluding vitamins)?		🟩	🟩	🟩	🟩
sayh_d33_FeedingTube	During the past week : Have you used a feeding tube?		🟩		🟩	🟩
sayh_d34_LostWeight	During the past week : Have you lost weight?		🟩			
sayh_d35_GainedWeight	During the past week : Have you gained weight?		🟩			
sayh_d36_HeartAttack	Have you ever been diagnosed by a medical professional as having : Heart Attack (myocardial infarction)?		⬛	⬛	⬛	🟩
sayh_d36a_HeartAttackAge	Have you ever been diagnosed by a medical professional as having : Heart Attack (myocardial infarction)? – Yes, at what age?		⬛	⬛	⬛	🟩
sayh_d37_HeartFailure	Have you ever been diagnosed by a medical professional as having : Heart failure?		⬛	⬛	⬛	🟩
sayh_d37a_HeartFailureAge	Have you ever been diagnosed by a medical professional as having : Heart failure? – Yes, at what age		⬛	⬛	⬛	🟩
sayh_d38_PeriphVasclrDis	Have you ever been diagnosed by a medical professional as having : Peripheral vascular disease (blocked arteries in your legs/poor circulation causing purple feet or hands)?		⬛	⬛	⬛	🟩
sayh_d38a_PeriphVasclrDisAge	Have you ever been diagnosed by a medical professional as having : Peripheral vascular disease (blocked arteries in your legs/poor circulation causing purple feet or hands)? – Yes, at what age		⬛	⬛	⬛	🟩
sayh_d39_ChrncObstLungDis	Have you ever been diagnosed by a medical professional as having : Chronic obstructive lung disease (COPD), or chronic bronchitis?		⬛	⬛	⬛	🟩
sayh_d39a_ChrncObstLngDisAge	Have you ever been diagnosed by a medical professional as having : Chronic obstructive lung disease (COPD), or chronic bronchitis? – Yes, at what age		⬛	⬛	⬛	🟩
sayh_d40_Emphysema	Have you ever been diagnosed by a medical professional as having : Emphysema?		⬛	⬛	⬛	🟩
sayh_d40a_EmphysemaAge	Have you ever been diagnosed by a medical professional as having : Emphysema? – Yes, at what age		⬛	⬛	⬛	🟩
sayh_d41_StomachUlcers	Have you ever been diagnosed by a medical professional as having : Stomach ulcers proven by a test?		⬛	⬛	⬛	🟩
sayh_d41a_StomachUlcersAge	Have you ever been diagnosed by a medical professional as having : Stomach ulcers proven by a test? – Yes, at what age		⬛	⬛	⬛	🟩
sayh_d42_LiverDisease	Have you ever been diagnosed by a medical professional as having : Liver disease?		⬛	⬛	⬛	🟩

sayh_d42a_LiverDiseaseDesc	Have you ever been diagnosed by a medical professional as having : Liver disease? - Yes, please specify				
sayh_d42b_LiverDiseaseAge	Have you ever been diagnosed by a medical professional as having : Liver disease? – Yes, at what age				
sayh_d43_Hepatitis	Have you ever been diagnosed by a medical professional as having : Hepatitis ? (A, B or C or other?				
sayh_d43a_HepatitisDesc	Have you ever been diagnosed by a medical professional as having : Hepatitis ? (A, B or C or other? - Yes, please specify				
sayh_d43b_HepatitisAge	Have you ever been diagnosed by a medical professional as having : Hepatitis ? (A, B or C or other? – Yes, at what age				
sayh_d44_Stroke	Have you ever been diagnosed by a medical professional as having : A stroke/mini-stroke?				
sayh_d44a_StrokeAge	Have you ever been diagnosed by a medical professional as having : A stroke/mini-stroke? – Yes, at what age				
sayh_d45_Hemiplegia	Have you ever been diagnosed by a medical professional as having : Do you have hemiplegia (weakness/paralysis of arms/legs)?				
sayh_d45a_HemiplegiaAge	Have you ever been diagnosed by a medical professional as having : Do you have hemiplegia (weakness/paralysis of arms/legs)? – Yes, at what age				
sayh_d46_Dementia	Have you ever been diagnosed by a medical professional as having : Dementia (e.g. Alzheimer's)?				
sayh_d46a_DementiaAge	Have you ever been diagnosed by a medical professional as having : Dementia (e.g. Alzheimer's)? – Yes, at what age				
sayh_d47_RhmtoidArthrts	Have you ever been diagnosed by a medical professional as having : Rheumatoid arthritis (this is NOT osteoarthritis)?				
sayh_d47a_RhmtoidArthrtsAge	Have you ever been diagnosed by a medical professional as having : Rheumatoid arthritis (this is NOT osteoarthritis)? – Yes, at what age				
sayh_d48_Lupus	Have you ever been diagnosed by a medical professional as having : Lupus (SLE), Scleroderma, Sjögren's, or connective tissue disease?				
sayh_d48a_LupusAge	Have you ever been diagnosed by a medical professional as having : Lupus (SLE), Scleroderma, Sjögren's, or connective tissue disease? – Yes, at what age				
sayh_d49_OthJntBonePrbs	Have you ever been diagnosed by a medical professional as having : Other joint/bone problems?				
sayh_d49a_OthJntBonePrbsDesc	Have you ever been diagnosed by a medical professional as having : Other joint/bone problems? - yes, please specify type				
sayh_d49b_OthJntBonePrbsAge	Have you ever been diagnosed by a medical professional as having : Other joint/bone problems? – Yes, at what age				

sayh_d50_SeriousKdnyPrbs	Have you ever been diagnosed by a medical professional as having : Serious kidney problems?				
sayh_d50a_SeriousKdnPrbsDesc	Have you ever been diagnosed by a medical professional as having : Serious kidney problems? - Yes, please specify				
sayh_d50b_SeriousKdnPrbsAge	Have you ever been diagnosed by a medical professional as having : Serious kidney problems? – Yes, at what age				
sayh_d51_ReqdDialysis	Have you ever been diagnosed by a medical professional as having : Have you ever required dialysis?				
sayh_d51a_ReqdDialysisAge	Have you ever been diagnosed by a medical professional as having : Have you ever required dialysis? – Yes, at what age				
sayh_d52_SufferFrmDiabts	Have you ever been diagnosed by a medical professional as having : Do you suffer from diabetes?				
sayh_d52a_SufferFrmDiabtsAge	Have you ever been diagnosed by a medical professional as having : Do you suffer from diabetes? – Yes, at what age				
sayh_d52b1_EyePrbsDiabts	Have you ever been diagnosed by a medical professional as having : Do you suffer from diabetes? – Yes, have you ever had Eye problems due to your diabetes?				
sayh_d52b2_EyePrbsDiabtsAge	Have you ever been diagnosed by a medical professional as having : Do you suffer from diabetes? – Yes, have you ever had Eye problems due to your diabetes? – Yes, at what age				
sayh_d52c1_KdnyPrbsDiabts	Have you ever been diagnosed by a medical professional as having : Do you suffer from diabetes? – Yes, have you ever had Kidney problems due to your diabetes?				
sayh_d52c2_KdnyPrbsDiabtsAge	Have you ever been diagnosed by a medical professional as having : Do you suffer from diabetes? – Yes, have you ever had Kidney problems due to your diabetes? – Yes, at what age				
sayh_d53_HIVAIDS	Have you ever been diagnosed by a medical professional as having : HIV/AIDS? (this will remain strictly confidential)				
sayh_d53a_HIVAIDSAge	Have you ever been diagnosed by a medical professional as having : HIV/AIDS? (this will remain strictly confidential) – Yes, at what age				
sayh_d54a_PastCancerNone	Past Cancer History: Please fill in the table below if you have ever been diagnosed with any type of cancer before the current diagnosis (include leukaemia, lymphoma, and skin cancers like melanoma, basal cell or squamous cell skin cancer): Or tick None and go to question D55.				
sayh_d54a1a_PastCancerName	Type of Cancer (e.g. breast, lung, etc.)				
sayh_d54a1b_DteOfDiagn	Date of diagnosis	dv_days_frm_cnsnt_to_d54a1b			
sayh_d54a1c_DteOfDiagDtls	Known accuracy of date given.				
sayh_d54a1d_HwWereYuTrtd	How were you treated? (surgery, chemo, radiation, etc)				

sayh_d54a1e_DuratnOfTx	Duration of treatment (months as default)					
sayh_d54a1f_DuratnOfTxUnits	Known accuracy of date given.					
sayh_d54a2a_PastCancerName	Type of Cancer (e.g. breast, lung, etc.)					
sayh_d54a2b_DteOfDiagn	Date of diagnosis	dv_days_frm_cnsnt_to_d54a2b				
sayh_d54a2c_DteOfDiagDtls	Known accuracy of date given.					
sayh_d54a2d_HwWereYuTrtd	How were you treated? (surgery, chemo, radiation, etc)					
sayh_d54a2e_DuratnOfTx	Duration of treatment (months as default)					
sayh_d54a2f_DuratnOfTxUnits	Known accuracy of date given.					
sayh_d54a3a_PastCancerName	Type of Cancer (e.g. breast, lung, etc.)					
sayh_d54a3b_DteOfDiagn	Date of diagnosis	dv_days_frm_cnsnt_to_d54a3b				
sayh_d54a3c_DteOfDiagDtls	Known accuracy of date given.					
sayh_d54a3d_HwWereYuTrtd	How were you treated? (surgery, chemo, radiation, etc)					
sayh_d54a3e_DuratnOfTx	Duration of treatment (months as default)					
sayh_d54a3f_DuratnOfTxUnits	Known accuracy of date given.					
sayh_d54a4a_PastCancerName	Type of Cancer (e.g. breast, lung, etc.)					
sayh_d54a4b_DteOfDiagn	Date of diagnosis	dv_days_frm_cnsnt_to_d54a4b				
sayh_d54a4c_DteOfDiagDtls	Known accuracy of date given.					
sayh_d54a4d_HwWereYuTrtd	How were you treated? (surgery, chemo, radiation, etc)					
sayh_d54a4e_DuratnOfTx	Duration of treatment (months as default)					
sayh_d54a4f_DuratnOfTxUnits	Known accuracy of date given.					
sayh_d54a5a_PastCancerName	Type of Cancer (e.g. breast, lung, etc.)					
sayh_d54a5b_DteOfDiagn	Date of diagnosis	dv_days_frm_cnsnt_to_d54a5b				
sayh_d54a5c_DteOfDiagDtls	Known accuracy of date given.					
sayh_d54a5d_HwWereYuTrtd	How were you treated? (surgery, chemo, radiation, etc)					
sayh_d54a5e_DuratnOfTx	Duration of treatment (months as default)					
sayh_d54a5f_DuratnOfTxUnits	Known accuracy of date given.					
sayh_d54b_HaveHadChemo	Have you ever had chemotherapy?					
sayh_d55_CervclCncr	If you are a woman, have you ever been told by a doctor that you have cervical cancer? (cancer of the womb)					
sayh_d56_CervclCncrPrtnr	If you are a man, has your current partner or a former partner ever been told by a doctor that they have cervical cancer? (cancer of the womb)					
sayh_d57_Tnsllctmy	Have you ever had surgery to remove your tonsils (a tonsillectomy)? (If you ticked "No" or "Not sure", please go to question D59)					
sayh_d58_TnsllctmyPriHN	Were your tonsils removed before you developed head and neck cancer?					
sayh_d59_HNTmrComeBack	Since you received your original head and neck cancer diagnosis, have you been told by your doctor that your head and neck tumour has come back?					
sayh_d60a_HNTmrRecMonth	If your head and neck tumour has come back, when was this? : Month					

Variable Name	Definition				
sayh_d60b_HNTmrRecYear	If your head and neck tumour has come back, when was this? : Year				
sayh_d61a1_HNTmrRecTxNone	What type of treatment (if any) have you received for this? Please tick all that apply : None				
sayh_d61a2_HNTmrRecTxRadio	What type of treatment (if any) have you received for this? Please tick all that apply : Radiotherapy				
sayh_d61a3_HNTmrRecTxChemo	What type of treatment (if any) have you received for this? Please tick all that apply : Chemotherapy				
sayh_d61a4_HNTmrRecTxSurg	What type of treatment (if any) have you received for this? Please tick all that apply : Surgery				
sayh_d61a5_HNTmrRecTxOth	What type of treatment (if any) have you received for this? Please tick all that apply : Other				
sayh_d61a5a_HNTmrRecTxOthDesc	If you selected "Other", please specify what treatment you received:				
sayh_d62_HasTxFinished	If you received treatment, has this finished?				

5.2.5 Section E – Your Feelings (These HADs question scores are summarised as in the Derived Variables section below, and these will be included with this sections data)

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
yf_e1_Tense	I feel tense or 'wound up'				
yf_e2_EnjoyThings	I still enjoy the things I used to enjoy				
yf_e3_FrghtndAwful	I get a sort of frightened feeling as if something awful is about to happen				
yf_e4_Laugh	I can laugh and see the funny side of things				
yf_e5_WorryingThoughts	Worrying thoughts go through my mind				
yf_e6_FeelCheerful	I feel cheerful				
yf_e7_FeelRelaxed	I can sit at ease and feel relaxed				
yf_e8_SlowedDown	I feel as if I am slowed down				
yf_e9_FrghtndBttrflies	I get a sort of frightened feeling like 'butterflies' in the stomach				
yf_e10_LstIntrstInApprnc	I have lost interest in my appearance				
yf_e11_Restless	I feel restless as I have to be on the move				
yf_e12_LookForward	I look forward with enjoyment to things				
yf_e13_FeelingsOfPanic	I get sudden feelings of panic				
yf_e14_EnjoyRadioTv	I can enjoy a good book or radio or TV program				
dv_hads_anx_scr	HADs aggregate scoring. **Refer to derived variables table**				
dv_hads_dprsn_scr	HADs aggregate scoring. **Refer to derived variables table**				
dv_hads_anx_scr_grp_txt	HADs aggregate scoring. **Refer to derived variables table**				
dv_hads_dprsn_scr_grp_txt	HADs aggregate scoring. **Refer to derived variables table**				

5.2.6   Section F – Your Diet

Variable Name	Definition	Timepoints HN1	HN2	HN3	HN4
yd_f1_ServingsOfFruit	In summary, how many servings of fruit do you usually eat, not counting juices?	■	■	■	■
yd_f2_ServingsOfVeg	In summary, how many servings of vegetables do you usually eat, not counting salad or potatoes?	■	■	■	■
yd_f3_FriedFood	In summary, how often do you eat deep fried food (e.g. French fries, fried chicken, fried fish, fried clams, fried shrimp etc.)?	■	■	■	■
yd_f4_EtngHabits	Do you feel that your eating habits have returned to how they were before your head and neck cancer? By eating habits, we mean the types and quantities of foods that you eat.				■
yd_f5a_EtngHbtsNrmHwLngYrs	If you feel that your eating habits have returned to how they were before your diagnosis, about how long did this take? : Years				■
yd_f5b_EtngHbtsNrmHwLngMths	If you feel that your eating habits have returned to how they were before your diagnosis, about how long did this take? : Months				■
yd_f6a_PrbEtngSpicyFoods	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Spicy foods				■
yd_f6b_PrbEtngBlackPepper	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Black Pepper				■
yd_f6c_PrbEtngSweetFoods	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Sweet foods				■
yd_f6d_PrbEtngSourFoods	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Sour foods				■
yd_f6e_PrbEtngSaltyFoods	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Salty foods				■
yd_f6f_PrbEtngHotFoods	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Hot foods				■
yd_f6g_PrbEtngColdFoods	Since receiving treatment for head and neck cancer have you had any problems eating the following foods? Please tick all that apply : Cold foods				■
yd_f7a_ChgsSmellOfFood	Have you experienced any changes to the smell of food?				■
yd_f7b1_WhtChgsCmpltLssSmll	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : Complete loss of smell				■
yd_f7b2_WhtchgsRdcdSmll	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : Reduced sensitivity to smells				■
yd_f7b3_WhtchgsInbltyDscrm	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : Inability to discriminate between different smells				■
yd_f7b4_WhtchgsAwrnssSmlls	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : Awareness of smells that weren't there				■
yd_f7b5_WhtchgsHghtndSmll	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : A heightened sense of smell				■

yd_f7b6_WhtchgsOth	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : Other				
yd_f7b61_WhtchgsOthDesc	Have you experienced any changes to the smell of food? If so, what kind of changes did you experience? : Other - Please specify				
yd_f8_SmellRetrndToNormal	If you have experienced changes to your sense of smell, has this now returned to normal?				
yd_f9_ExperimntedCooking	Have you experimented with new cooking approaches or food preparation techniques since your treatment for head and neck cancer?				
yd_f10_ThrowingFoodAway	Are you throwing more food away since receiving your treatment?				
yd_f11_TakeAntacids	Do you take antacids regularly?				
yd_f12_AntacidsPrescribed	Do you take antacids regularly? : Are these antacids prescribed by your doctor?				
yd_f13_AntacidsName	Do you take antacids regularly? : Please give the name of the antacids that you take				
yd_f14_AntacidsHowOften	Do you take antacids regularly? : How often do you take antacids?				
yd_f15_FdngTube	After your initial treatment, did you have a feeding tube in place?				
yd_f16a_FdngTubeHwLngDays	If you did have a feeding tube in place, how long was it for? : Days				
yd_f16b_FdngTubeHwLngWks	If you did have a feeding tube in place, how long was it for? : Weeks				
yd_f16c_FdngTubeHwLngMnths	If you did have a feeding tube in place, how long was it for? : Months				
yd_f16d_FdngTubeHwLngStllHve	If you did have a feeding tube in place, how long was it for? : I still have my feeding tube				
yd_f17a_FdngTubeHwLngDays	How long did you use your feeding tube for? : Days				
yd_f17b_FdngTubeHwLngWks	How long did you use your feeding tube for? : Weeks				
yd_f17c_FdngTubeHwLngMnths	How long did you use your feeding tube for? : Months				
yd_f18a_FdngTubeAlsoEatByMth	During the time that you used your feeding tube, did you also eat by mouth?				
yd_f18b_HowOftnDidEatByMth	During the time that you used your feeding tube, did you also eat by mouth? : How often did you eat by mouth?				
yd_f19a_RsnsEatByMthTaste	What were your reasons for continuing to eat by mouth in addition to using your feeding tube? : For the taste				
yd_f19b_RsnsEatByMthTexture	What were your reasons for continuing to eat by mouth in addition to using your feeding tube? : For the texture				
yd_f19c_RsnsEatByMthNourish	What were your reasons for continuing to eat by mouth in addition to using your feeding tube? : For the nourishment				
yd_f19d_RsnsEatByMthNormal	What were your reasons for continuing to eat by mouth in addition to using your feeding tube? : To feel more normal				
yd_f19e_RsnsEatByMthOth	What were your reasons for continuing to eat by mouth in addition to using your feeding tube? : Other				
yd_f19e1_RsnsEatByMthOthDesc	What were your reasons for continuing to eat by mouth in addition to using your feeding tube? : Other - Please specify				
yd_f20_AvoidEatByMouth	Did you avoid eating by mouth in front of others?				

5.2.7 Section G – Thoughts around cancer recurrence

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
yc_g1_AfraidCncrRec	I am afraid that my cancer may recur.				
yc_g2_WorriedCncrRec	I am worried about the possibility of cancer recurrence.				
yc_g3_HwOftWrriedCncrRec	How often have you worried about the possibility of getting cancer again?				
yc_g4_StrngFlingsCncrRec	I get waves of strong feelings about the cancer coming back.				

5.2.8 Section H – Your personal costs

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
ypc_h1_PdForMedctn	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for any kind of medication? (e.g. conventional, alternative)				
ypc_h1a_PdForMedctnTypes	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for any kind of medication? (e.g. conventional, alternative) : Type(s) of medication				
ypc_h1b_PdForMedctnAprxAmnt	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for any kind of medication? (e.g. conventional, alternative) : Approximate amount				
ypc_h2_PdForTx	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for any kind of treatment, i.e. private health care? (e.g. conventional, alternative)				
ypc_h2a_PdForTxTypes	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for any kind of treatment, i.e. private health care? (e.g. conventional, alternative) : Type(s) of medication				
ypc_h2b_PdForTxAprxAmnt	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for any kind of treatment, i.e. private health care? (e.g. conventional, alternative) : Approximate amount				
ypc_h3_PdFrHmeHlp	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for home help?				
ypc_h3a_PdFrHmeHlpAprxAmnt	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Paid for home help? : Approximate amount				
ypc_h4_TrvlExpns	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Incurred any **travel expenses** for your hospital/clinic appointments? (e.g. train fares, bus fares, petrol, parking costs, overnight accommodation)				

Variable	Description			
ypc_h4a_TrvlExpnsAprxAmnt	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Incurred any other out-of-pocket expenses? (e.g. special dietary items, pain relief) : Approximate amount		✔	✔
ypc_h5_OthOutOfPckt	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Incurred any other out-of-pocket expenses? (e.g. special dietary items, pain relief)		✔	✔
ypc_h5a_OthOutOfPcktTypes	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Incurred any other out-of-pocket expenses? (e.g. special dietary items, pain relief) : Type(s) of expenditure			
ypc_h5b_OthOutOfPcktAprxAmnt	Please think of the last year and answer each of the following questions in relation to yourself and/or any member of your immediate family : Incurred any other out-of-pocket expenses? (e.g. special dietary items, pain relief) : Approximate amount			
ypc_h6_TknTmeOffWrk	Have you taken **time off work** because of your illness?			
ypc_h6a_TknTmeOffWrkWks	Have you taken **time off work** because of your illness? : Number of weeks			
ypc_h6a_TknTmeOffWrkMths	Have you taken **time off work** because of your illness? : Number of months			
ypc_h7_FamTknTmeOffWrk	Has a member of your immediate family taken **time off work** because of your illness?			
ypc_h7a_FamTknTmeOffWrkWks	Has a member of your immediate family taken **time off work** because of your illness? : Number of weeks			
ypc_h7a_FamTknTmeOffWrkMths	Has a member of your immediate family taken **time off work** because of your illness? : Number of months			
ypc_h8_RductnIncm	Have you suffered any **reduction of income** as a result of taking time off work because of your illness?			
ypc_h8a_RductnIncmAprxAmnt	Have you suffered any **reduction of income** as a result of taking time off work because of your illness? : Approximate amount of gross income that has been lost in total			
ypc_h9_FamRdctnIncm	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?			
ypc_h9a_FamRdctnIncmAprxAmnt	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? : Approximate amount of gross income that has been lost in total			
ypc_h10_GvUpWrk	Have you **given up work completely** because of your illness?			
ypc_h10a_GvUpWrkkAprxAmnt	Have you **given up work completely** because of your illness? : Approximate amount of gross income that has been lost in total			
ypc_h11_FamGvUpWrk	Has any member of your immediate family **given up work completely** because of your illness?			
ypc_h11a_FamGvnUpWrkAprxAmnt	Has any member of your immediate family **given up work completely** because of your illness? : Approximate amount of gross income that has been lost in total			
ypc_h12_DiffsMrtgeOrRnt	Have you run into difficulties with paying the **mortgage or rent** for the property where you live?			
ypc_h12a_DiffsMrtgeNoOfMth	Have you run into difficulties with paying the **mortgage or rent** for the property where you live? : Number of months having this difficulty			
ypc_h12b_MrtgeOrRntAprxAmnt	Have you run into difficulties with paying the **mortgage or rent** for the property where you live? : Approximate amount of mortgage or rent per month			

5.2.9 Section I – Your quality of life (Data only collected at three sites)

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
yql_i1_Pain	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 : **Pain**	🟩	🟩	🟩	⬛
yql_i2_Appearance	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 : **Appearance**	🟩	🟩	🟩	⬛
yql_i3_Activity	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 : **Activity**	🟩	🟩	🟩	⬛
yql_i4_Recreation	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 : **Recreation**	🟩	🟩	🟩	⬛
yql_i5_Swallowing	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 : **Swallowing**	🟩	🟩	🟩	⬛
yql_i6_Chewing	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 : **Chewing**	🟩	🟩	🟩	⬛
yql_i7_Speech	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 : **Speech**	🟩	🟩	🟩	⬛
yql_i8_Shoulder	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 : **Shoulder**	🟩	🟩	🟩	⬛
yql_i9_Taste	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 : **Taste**	🟩	🟩	🟩	⬛
yql_i10_Saliva	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 : **Saliva**	🟩	🟩	🟩	⬛
yql_i11_Mood	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 : **Mood**	🟩	🟩	🟩	⬛
yql_i12_Anxiety	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 : **Anxiety**	🟩	🟩	🟩	⬛
yql_i13a_Issues1	**Which issues have been the most important to you during the past 7 days?** : Choice 1	🟩	🟩	🟩	⬛
yql_i13b_Issues2	**Which issues have been the most important to you during the past 7 days?** : Choice 2	🟩	🟩	🟩	⬛
yql_i13c_Issues3	**Which issues have been the most important to you during the past 7 days?** : Choice 3	🟩	🟩	🟩	⬛
yql_i14_QoLMonth	Compared to the month before you developed cancer, how would you rate your health- related quality of life?	🟩	🟩	🟩	⬛
yql_i15_QoLWeek	In general, would you say your *health-related quality of life* during the past 7 days has been.	🟩	🟩	🟩	⬛
yql_i16_WellBeing	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.	🟩	🟩	🟩	⬛

Variable Name	Definition				
yql_i17_Items	Please indicate on the following lines any items (medical or non-medical) that are important to your quality of life and have not been adequately addressed in the above questions and statements.				

5.2.10 Section J – Difficulties in your life (Data only collected at three sites)

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
dyl_j1_Independence	**During the past month:** Have you had any difficulty maintaining your independence?				
dyl_j2_DomesticChores	**During the past month:** Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)				
dyl_j3_PersonalCare	**During the past month:** Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)				
dyl_j4_Dependents	**During the past month:** Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)				
dyl_j5_Support	**During the past month:** Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?				
dyl_j6_Benefits	**During the past month:** Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)				
dyl_j7_FinancialDif	**During the past month:** Have you had any financial difficulties?				
dyl_j8_FinancialServices	**During the past month:** Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)				
dyl_j9_DfcltyWork	**During the past month:** Have you had any difficulty concerning your work? (or education if you are a student)				
dyl_j10_DfcltyPlanFuture	**During the past month:** Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)				
dyl_j11_CmmnctngClosest	**During the past month:** Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)				
dyl_j12_CmmnctngOth	**During the past month:** Have you had any difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)				
dyl_j13_SexualMatters	**During the past month:** Have you had any difficulty concerning sexual matters?				
dyl_j14_DiffPlansHvngFam	**During the past month:** Have you had any difficulty concerning plans to have a family?				
dyl_j15_BodyImage	**During the past month:** Have you had any difficulty concerning your appearance or body image?				
dyl_j16_FeltIsolated	**During the past month:** Have you felt isolated?				
dyl_j17_Mobility	**During the past month:** Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)				
dyl_j18_DfcltyWhereYouLive	**During the past month:** Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)				
dyl_j19_DfcltyWhereYouLive	**During the past month:** Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)				

| dyl_j20_DfcltyTravel | **During the past month:** Have you had any difficulty with your plans to travel or take a holiday? | | | | |
| dyl_j21_DfcltyAnyOthArea | **During the past month:** Have you had any difficulty with any other area of your everyday life? | | | | |

5.2.11 Section K – Your appearance (Data only collected at three sites)

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
ya_k1a_ApprnceOfHN	Is there any aspect of the appearance of your head/neck (however small) that concerns you at all?				
ya_k2a_AspectOfHN	The aspect of my head/neck about which I am most sensitive or self-conscious is…				
ya_k3a_ThngDntLkeApprnceHN	The thing I don't like about the appearance of my head/neck is…				
ya_k4a_BodyDontLike	If you are sensitive or concerned about any other features of your body or your appearance, please say what they are.				
ya_k1b_HowConfident	How confident do you feel?				
ya_k2b_HowDistrssdMirror	How distressed do you get when you see yourself in the mirror/window?				
ya_k3b_SelfcnscsIrritable	My self-consciousness makes me irritable at home				
ya_k4b_HowHurtFeel	How hurt do you feel?				
ya_k5b_SelfcnscsWork	At present my self-consciousness has an adverse effect on my work				
ya_k6b_DistressedBeach	How distressed do you get when you go to the beach?				
ya_k7b_MisjudgeMe	Other people mis-judge me because of the appearance of my head/neck				
ya_k8b_HowFemMascFeel	How feminine/masculine do you feel?				
ya_k19b_DistressedSocial	How distressed do you get when going to social events?				
ya_k20b_HowNormalFeel	How normal do you feel?				
ya_k21b_EffectSexLife	At present my self-consciousness has an adverse effect on my sex life				
ya_k22b_AvoidGoingOut	I avoid going out of the house				
ya_k23b_DistressedRemarks	How distressed do you get when other people make remarks about the appearance of your head/neck?				
ya_k24b_AvoidPubs	I avoid going to pubs/restaurants				
ya_k1c_FeaturesPain	My feature causes me physical pain/discomfort				
ya_k2c_PhysicalAbility	My feature limits my physical ability to do the things I want to do				
ya_k3c_DisfigurementCncr	To what extent is any disfigurement or change to your appearance as a result of your cancer or its treatment noticeable to other people				
ya_k5c_TreatmentLook	How much will your treatment change the way you look?				
ya_k6c_BotherYou	How much does this bother you?				

5.2.12 Section L – Late Toxicity (Data only collected for participants who had radiotherapy treatment)

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
lt_l1_PainSeverity	How severe is the pain?			✓	✓
lt_l2a_WhrIsPainMouth	Where is the pain? *(tick all that apply)* : *Mouth*			✓	✓
lt_l2b_WhrIsPainThroat	Where is the pain? *(tick all that apply)* : *Throat*			✓	✓
lt_l2c_WhrIsPainJaw	Where is the pain? *(tick all that apply)* : *Jaw*			✓	✓
lt_l2d_WhrIsPainNeck	Where is the pain? *(tick all that apply)* : *Neck*			✓	✓
lt_l2e_WhrIsPainSkin	Where is the pain? *(tick all that apply)* : Skin			✓	✓
lt_l2f_WhrIsPainEar	Where is the pain? *(tick all that apply)* : Ear			✓	✓
lt_l2g_WhrIsPainOth	Where is the pain? *(tick all that apply)* : Other			✓	✓
lt_l2g1_WhrIsPainOthDesc	Where is the pain? *(tick all that apply)* : Other, please state			✓	✓
lt_l3_PainMeds	Are you taking any medication for this pain?			✓	✓
lt_l4a1_PainMedsName	Medication 1 name			✓	✓
lt_l4b1_PainMedsFreq	Medication 1 frequency			✓	✓
lt_l4a2_PainMedsName	Medication 2 name			✓	✓
lt_l4b2_PainMedsFreq	Medication 2 frequency			✓	✓
lt_l4a3_PainMedsName	Medication 3 name				✓
lt_l4b3_PainMedsFreq	Medication 3 frequency				✓
lt_l4a4_PainMedsName	Medication 4 name				✓
lt_l4b4_PainMedsFreq	Medication 4 frequency				✓
lt_l4a5_PainMedsName	Medication 5 name				✓
lt_l4b5_PainMedsFreq	Medication 5 frequency				✓
lt_l4a6_PainMedsName	Medication 6 name				✓
lt_l4b6_PainMedsFreq	Medication 6 frequency				✓
lt_l4a7_PainMedsName	Medication 7 name				✓
lt_l4b7_PainMedsFreq	Medication 7 frequency				✓
lt_l4a8_PainMedsName	Medication 8 name				✓
lt_l4b8_PainMedsFreq	Medication 8 frequency				✓
lt_l4a9_PainMedsName	Medication 9 name				✓
lt_l4b9_PainMedsFreq	Medication 9 frequency				✓
lt_l4a10_PainMedsName	Medication 10 name				✓
lt_l4b10_PainMedsFreq	Medication 10 frequency				✓
lt_l4a11_PainMedsName	Medication 11 name				✓
lt_l4b11_PainMedsFreq	Medication 11 frequency				✓
lt_l5_PainMedsIntrfrSlfCre	Does the pain or painkillers interfere with daily self-care activities (E.g. bathing, getting about indoors, dressing, getting in / out of bed)			✓	✓

lt_l6_LostAppetite	Have you lost your appetite?		
lt_l7_DiffsSwallowing	Have you had difficulties in swallowing?		
lt_l8_DiffsOpeningMouth	Have you any difficulty opening your mouth?		
lt_l9_AlterationInTaste	Do you have any alteration in your taste?		
lt_l10_LossTaste	If yes, have you had any loss of taste and / or do you find taste unpleasant?		
lt_l11_DryMouth	Have you had a dry mouth?		
lt_l12_ChangesToSaliva	Have you had any changes to your saliva?		
lt_l13_AffctdTaste	If yes, has it affected your taste?		
lt_l14_SalAffctDailySlfCre	If you have saliva changes, how has it affected your daily self-care activities? (E.g. bathing, getting about Indoors dressing, getting in / out of bed)		
lt_l15_DietSigAffctd	Has your diet been significantly affected?		
lt_l16a_DietAffectSwllwng	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Difficulty in swallowing		
lt_l16b_DietAffctDryMth	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Dry mouth		
lt_l16c_DietAffctDiffOpnMth	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Difficulty opening mouth		
lt_l16d_DietAffctLssApptt	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Loss of appetite		
lt_l16e_DietAffctAltrdTste	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Altered taste		
lt_l16f_DietAffctChngInSal	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Change in saliva		
lt_l16g_DietAffctOth	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Other		
lt_l16g1_DietAffctOthDesc	If your diet has been significantly affected, what has caused it? *(tick all that apply)* : Other, please state		
lt_l17a_NutrtDrnk	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Not on supplementary drinks		
lt_l17b_NutrtDrnkSwallowing	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Difficulty in swallowing		
lt_l17c_NutrtDrnkWghtLss	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Weight loss		
lt_l17d_NutrtDrnkLssApptt	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Loss of appetite		
lt_l17e_NutrtDrnkAlteredTaste	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Altered taste		
lt_l17f_NutrtDrnkOther	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Other		
lt_l17f1_NutrtDrnkOthDesc	If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)* : Other, please state		
lt_l18_SknFlkng	Have you any visible roughness or flaking of your skin		
lt_l19_SknFlkngObvious	If yes, how obvious is it?		
lt_l20_SknFlkngAffctApprn	If yes, does this affect your appearance?		
lt_l21_SknThckngHrdn	Have you any thickening or hardening of your skin (skin fibrosis)?		
lt_l22_SknThckngHrdnSvrty	If yes, how severe is the skin thickening / hardening?		
lt_l23_SknItchiness	Have you any skin itchiness?		
lt_l24_SknPuffnessHN	Do you have any puffiness in your head and neck?		

Variable Name	Definition			
lt_l25_SknPuffnessInterfr	If yes, has it interfered with any function (e.g. turning your head or opening mouth) compared with before radiotherapy?	⬛	🟩	🟩
lt_l26_VceHoarseness	Are you getting any hoarseness / voice changes?	⬛	🟩	🟩
lt_l27_VceHoarsenessSevr	If you have hoarseness / voice change, how severe is it?	⬛	🟩	🟩
lt_l28_VceUnderstood	Can your voice be understood?	⬛	🟩	🟩
lt_l29_HringLoss	Have you had any hearing loss?	⬛	🟩	🟩
lt_l30_HringLossSevr	If yes, how severe has this been?	⬛	🟩	🟩
lt_l31_HringAid	Do you require a hearing aid?	⬛	🟩	🟩
lt_l32_HringNoiseRinging	Are you getting any noise or ringing in your ears?	⬛	🟩	🟩
lt_l33_RngngAffctSlfCare	If yes, how has it affected your daily self-care activities? (e.g. bathing, getting about indoors, dressing, getting in / out of bed)	⬛	🟩	🟩

5.2.13 Section M – Sexual History

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
sh_m1_AgeFirstHadSex	How old were you when you first had sexual intercourse?	🟩			
sh_m2_NumSexPrtnr	How many different sexual partners have you had in your lifetime?	🟩			
sh_m3a_OralSex	Have you ever performed oral sex on a partner?	🟩			
sh_m3b_NumOralSex	If yes, how many different sexual partners have you performed oral sex on?	🟩			
sh_m4a_SameSexPrtnr	Have you ever had sex with a same sex partner?	🟩			
sh_m4b_NumSameSexPrtnr	If yes, how many different same sex partners have you had in your lifetime?	🟩			
sh_m5_DiagGntlWarts	Have you ever been diagnosed or treated for genital warts?	🟩			
sh_m6_PrtnrDiagGntlWarts	Have you ever had a sexual partner who had genital warts?	🟩			
sh_m7a_FemAbPapSmear	If female, have you ever had an abnormal pap smear?	🟩			
sh_m7b_MlePrtnrAbPapSmear	If male, have any of your sexual partners ever had an abnormal pap smear?	🟩			
sh_m8a_FemDiagCervCanc	If female, have you ever been diagnosed with cervical cancer?	🟩			
sh_m8b_MlePrtnrDiagCervCanc	If male, have any of your sexual partners ever been diagnosed with cervical cancer?	🟩			
sh_m9_Circumcised	If male, are you circumcised?	🟩			

5.2.14 Section T – Your Dental Health

Variable Name	Definition	Timepoints			
		HN1	HN2	HN3	HN4
ydh_t1_HowManyNaturalTth	Adults can have up to 32 natural teeth but over time people lose some of them. How many natural teeth, including crowns have you got?				▉
ydh_t2a_HappyApprnceTth	Are you happy with the appearance of your teeth at present?				▉
ydh_t2b_Toothache	Do you have any toothache or pain in your mouth?				▉
ydh_t2c_DiffsBitingChwing	Do you have any problems or difficulties biting or chewing food?				▉
ydh_t2d_DoGumsBleed	Do your gums bleed when you eat or brush your teeth				▉
ydh_t3_VstDntst	About how long ago was your last visit to the "high street" dentist?				▉
ydh_t4a_VstDntstTmeOffWrk	Visiting the dentist – Do any of the following apply to you? : It is difficult to get time off work to go				▉
ydh_t4b_VstDntstDiffGtApp	Visiting the dentist – Do any of the following apply to you? : It is difficult getting an appointment that suits me				▉
ydh_t4c_VstDntstTooExpnsv	Visiting the dentist – Do any of the following apply to you? : I find dental treatment too expensive				▉
ydh_t4d_VstDntstLongWay	Visiting the dentist – Do any of the following apply to you? : It is a long way to go to the dentist				▉
ydh_t4e_VstDntstNotLike	Visiting the dentist – Do any of the following apply to you? : I have not found a dentist I like				▉
ydh_t4f_VstDntstCantGtNHS	Visiting the dentist – Do any of the following apply to you? : I cannot get dental treatment under the NHS 6				▉
ydh_t4g_VstDntstDiffAcc	Visiting the dentist – Do any of the following apply to you? : I have difficulty in getting access, e.g. steps, wheelchair access				▉
ydh_t4h_VstDntstMngEffct	Visiting the dentist – Do any of the following apply to you? : I don't think my dentist knows enough about managing the effects of my cancer and its treatment on my mouth and teeth				▉
ydh_t4i_VstDntstHospital	Visiting the dentist – Do any of the following apply to you? : My dentist sends me back to the hospital because I have had cancer treatment				▉
ydh_t4j_VstDntstOth	Visiting the dentist – Do any of the following apply to you? : Other reason				▉
ydh_t4j1_VstDntitOthDesc	Visiting the dentist – Do any of the following apply to you? : Other reason (please explain)				▉

5.3 Site Completed Data Capture Form Variable Descriptions

5.3.1 Data Capture Form, Baseline (HN1), Section 1 - Detailed planned treatment (B2, B3)

Variable Name	Definition
dcf_b2a_SurgeryPrimary	Cancer treatment type (Planned at HN1, Actual at HN2) : A. Surgery (primary site)
dcf_b2b_SurgeryNeck	Cancer treatment type (Planned at HN1, Actual at HN2) : B. Surgery (neck dissection for lymph nodes in neck)
dcf_b2c_Teletherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : C. Teletherapy (Radiotherapy)
dcf_b2d_Chemotherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : D. Chemotherapy
dcf_b2e_Hormone	Cancer treatment type (Planned at HN1, Actual at HN2) : E. Hormone therapy
dcf_b2e1_HormoneDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : E. Hormone therapy - please state:
dcf_b2f_Specialist	Cancer treatment type (Planned at HN1, Actual at HN2) : F. Specialist palliative
dcf_b2g_Brachytherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : G. Brachytherapy
dcf_b2h_Biological	Cancer treatment type (Planned at HN1, Actual at HN2) : H. Biological
dcf_b2h1_BiologicalDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : H. Biological - please state:
dcf_b2i_Other	Cancer treatment type (Planned at HN1, Actual at HN2) : I. Other
dcf_b2i1_OtherDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : I. Other - please state:
dcf_b2j_Monitoring	Cancer treatment type (Planned at HN1, Actual at HN2) : J. Active monitoring
dcf_b2k_ChemoRadtherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : K. Combined chemoradiotherapy
dcf_b2l_Reconstruct	Cancer treatment type (Planned at HN1, Actual at HN2) : L. Reconstruction with free flap
dcf_b2m_LaserSurgery	Cancer treatment type (Planned at HN1, Actual at HN2) : M. Laser Surgery
dcf_b3a_TxSequence_1	Treatment type sequence : 1
dcf_b3b_TxSequence_2	Treatment type sequence : 2
dcf_b3c_TxSequence_3	Treatment type sequence : 3
dcf_b3d_TxSequence_4	Treatment type sequence : 4
dcf_b3e_TxSequence_5	Treatment type sequence : 5

5.3.2 Data Capture Form, Baseline (HN1), Section 2 - Pre-treatment staging (TNM) - (B5)

Variable Name	Definition
dcf_b5b_RecentTNM_T	TNM Category : T
dcf_b5c_RecentTNM_n	TNM Category : N
dcf_b5d_RecentTNM_m	TNM Category : M

5.3.3   Data Capture Form, Baseline (HN1), Section 3 - Laterality of tumour/nodes (B6, B7)

Variable Name	Definition
dcf_b6_SideTumor	Side of primary tumour
dcf_b7_SideDisease	Side of positive neck nodes

5.3.4   Data Capture Form, 4 month (HN2), Section 1 - Detailed received treatment (B1 - B3)

Variable Name	Definition
dcf_b1a_PlanIntent_1	Cancer plan intent (Planned at HN1, actual at HN2, plan of any further cancer treatment at HN3)
dcf_b1b_PlanIntent_2	Cancer plan intent (Planned at HN1, actual at HN2, plan of any further cancer treatment at HN3)
dcf_b1c_PlanIntent_3	Cancer plan intent (Planned at HN1, actual at HN2, plan of any further cancer treatment at HN3)
dcf_b2a_SurgeryPrimary	Cancer treatment type (Planned at HN1, Actual at HN2) : A. Surgery (primary site)
dcf_b2b_SurgeryNeck	Cancer treatment type (Planned at HN1, Actual at HN2) : B. Surgery (neck dissection for lymph nodes in neck)
dcf_b2c_Teletherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : C. Teletherapy (Radiotherapy)
dcf_b2d_Chemotherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : D. Chemotherapy
dcf_b2e_Hormone	Cancer treatment type (Planned at HN1, Actual at HN2) : E. Hormone therapy
dcf_b2e1_HormoneDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : E. Hormone therapy - please state:
dcf_b2f_Specialist	Cancer treatment type (Planned at HN1, Actual at HN2) : F. Specialist palliative
dcf_b2g_Brachytherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : G. Brachytherapy
dcf_b2h_Biological	Cancer treatment type (Planned at HN1, Actual at HN2) : H. Biological
dcf_b2h1_BiologicalDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : H. Biological - please state:
dcf_b2i_Other	Cancer treatment type (Planned at HN1, Actual at HN2) : I. Other
dcf_b2i1_OtherDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : I. Other - please state:
dcf_b2j_Monitoring	Cancer treatment type (Planned at HN1, Actual at HN2) : J. Active monitoring
dcf_b2k_ChemoRadtherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : K. Combined chemoradiotherapy
dcf_b2l_Reconstruct	Cancer treatment type (Planned at HN1, Actual at HN2) : L. Reconstruction with free flap
dcf_b2m_LaserSurgery	Cancer treatment type (Planned at HN1, Actual at HN2) : M. Laser Surgery
dcf_b3a_TxSequence_1	Treatment type sequence : 1
dcf_b3b_TxSequence_2	Treatment type sequence : 2
dcf_b3c_TxSequence_3	Treatment type sequence : 3
dcf_b3d_TxSequence_4	Treatment type sequence : 4
dcf_b3e_TxSequence_5	Treatment type sequence : 5

5.3.5 Data Capture Form, 4 month (HN2), Section 2 - Co-morbidity at 4-months (B4)

Variable Name	Definition
dcf_b4_ComorbIndex	Co-Morbidity index

5.3.6 Data Capture Form, 4 month (HN2), Section 3 - Definitive pre-treatment staging (B5)

Variable Name	Definition
dcf_b5b_RecentTNM_T	TNM Category : T
dcf_b5c_RecentTNM_n	TNM Category : N
dcf_b5d_RecentTNM_m	TNM Category : M

5.3.7 Data Capture Form, 4 month (HN2), Section 4 - Chemo/radiotherapy completion (B11 - B12a)

Variable Name	Definition	New Derived Variable Name
dcf_b10_StartDte	Procedure/Treatment start date	dv_days_frm_cnsnt_to_prcd_st
dcf_b11_RadiotherapyComplt	Was the initial course of radiotherapy treatment completed?	
dcf_b11a_RadiotherapyIncomp	If radiotherapy not completed, please give reason	
dcf_b12_ChemotherapyComplt	Was the initial course of chemotherapy treatment completed?	
dcf_b12a_ChemotherapyIncomp	If chemotherapy not completed, please give reason	

5.3.8 Data Capture Form, 4 month (HN2), Section 5 - Feed tube/tracheostomy (B13 - B15)

Variable Name	Definition
dcf_b13_FeedingPeg	Does the patient have a feeding tube?
dcf_b14_FeedingPegHowMuch	If patient has a feeding tube, approximately how much dietary intake is through the tube?
dcf_b15_Tracheostomy	Does the patient have a tracheostomy?

5.3.9 Data Capture Form, 4 month (HN2), Section 6 - Recurrence (B16 - B16a)

Variable Name	Definition
dcf_b16a_TumourRcrrnce	Has there been a tumour recurrence?
dcf_b16b_TmrRcrrnceTNM_T	Recurrence TNM Category : T
dcf_b16c_TmrRcrrnceTNM_N	Recurrence TNM Category : N
dcf_b16d_TmrRcrrnceTNM_M	Recurrence TNM Category : M

5.3.10 Data Capture Form, 12 month (HN3), Section 1 - Detailed received treatment since 4 months (B1 - B3)

Variable Name	Definition
dcf_b1a_PlanIntent_1	Cancer plan intent (Planned at HN1, actual at HN2, plan of any further cancer treatment at HN3)
dcf_b1b_PlanIntent_2	Cancer plan intent 2 (Planned at HN1, actual at HN2, plan of any further cancer treatment at HN3)
dcf_b1c_PlanIntent_3	Cancer plan intent 3 (Planned at HN1, actual at HN2, plan of any further cancer treatment at HN3)
dcf_b2a_SurgeryPrimary	Cancer treatment type (Planned at HN1, Actual at HN2) : A. Surgery (primary site)
dcf_b2b_SurgeryNeck	Cancer treatment type (Planned at HN1, Actual at HN2) : B. Surgery (neck dissection for lymph nodes in neck)
dcf_b2c_Teletherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : C. Teletherapy (Radiotherapy)
dcf_b2d_Chemotherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : D. Chemotherapy
dcf_b2e_Hormone	Cancer treatment type (Planned at HN1, Actual at HN2) : E. Hormone therapy
dcf_b2e1_HormoneDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : E. Hormone therapy - please state:
dcf_b2f_Specialist	Cancer treatment type (Planned at HN1, Actual at HN2) : F. Specialist palliative
dcf_b2g_Brachytherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : G. Brachytherapy
dcf_b2h_Biological	Cancer treatment type (Planned at HN1, Actual at HN2) : H. Biological
dcf_b2h1_BiologicalDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : H. Biological - please state:
dcf_b2i_Other	Cancer treatment type (Planned at HN1, Actual at HN2) : I. Other
dcf_b2i1_OtherDesc	Cancer treatment type (Planned at HN1, Actual at HN2) : I. Other - please state:
dcf_b2j_Monitoring	Cancer treatment type (Planned at HN1, Actual at HN2) : J. Active monitoring
dcf_b2k_ChemoRadtherapy	Cancer treatment type (Planned at HN1, Actual at HN2) : K. Combined chemoradiotherapy
dcf_b2l_Reconstruct	Cancer treatment type (Planned at HN1, Actual at HN2) : L. Reconstruction with free flap
dcf_b2m_LaserSurgery	Cancer treatment type (Planned at HN1, Actual at HN2) : M. Laser Surgery
dcf_b3a_TxSequence_1	Treatment type sequence : 1
dcf_b3b_TxSequence_2	Treatment type sequence : 2
dcf_b3c_TxSequence_3	Treatment type sequence : 3
dcf_b3d_TxSequence_4	Treatment type sequence : 4
dcf_b3e_TxSequence_5	Treatment type sequence : 5

5.3.11 Data Capture Form, 12 month (HN3), Section 2 - Co-morbidity at 4-months (B4)

Variable Name	Definition
dcf_b4_ComorbIndex	Co-Morbidity index

5.3.12 Data Capture Form, 12 month (HN3), Section 3 - Definitive pre-treatment staging (B5)

Variable Name	Definition
dcf_b5b_RecentTNM_t	TNM Category : T
dcf_b5c_RecentTNM_n	TNM Category : N
dcf_b5d_RecentTNM_m	TNM Category : M

5.3.13 Data Capture Form, 12 month (HN3), Section 4 - Chemo/radiotherapy completion (B10 - B12a)

Variable Name	Definition	New Derived Variable Name
dcf_b10_StartDte	Procedure/Treatment start date	dv_days_frm_cnsnt_to_prcd_st
dcf_b11_RadiotherapyComplt	Was the initial course of radiotherapy treatment completed?	
dcf_b11a_RadiotherapyIncomp	If radiotherapy not completed, please give reason	
dcf_b12_ChemotherapyComplt	Was the initial course of chemotherapy treatment completed?	
dcf_b12a_ChemotherapyIncomp	If chemotherapy not completed, please give reason	
dcf_b12b_FurtherTx	Was any further treatment completed?	

5.3.14 Data Capture Form, 12 month (HN3), Section 5 - Feed tube/tracheostomy (B13 - B15)

Variable Name	Definition
dcf_b13_FeedingPeg	Does the patient have a feeding tube?
dcf_b14_FeedingPegHowMuch	If patient has a feeding tube, approximately how much dietary intake is through the tube?
dcf_b15_Tracheostomy	Does the patient have a tracheostomy?

5.3.15 Data Capture Form, 12 month (HN3), Section 6 - Recurrence (B16 - B16a)

Variable Name	Definition
dcf_b16a_TumourRcrrnce	Has there been a tumour recurrence?
dcf_b16b_TmrRcrrnceTNM_T	Recurrence TNM Category : T
dcf_b16c_TmrRcrrnceTNM_N	Recurrence TNM Category : N
dcf_b16d_TmrRcrrnceTNM_M	Recurrence TNM Category : M
dcf_b17_NewPrimary	Has there been a new H&N primary?
dcf_b18_DiseaseFree	Is the patient clinically disease free?

5.3.16 Data Capture Form, 3-5 year follow-up (HN4), Section 1 - Intent of any current treatment (3 - 3b)

Variable Name	Definition	New Derived Variable Name
hn4_dcf_3_CancerPlanIntent	Please let us know the intent of the current cancer care plan for the patient's head and neck cancer. If the treatment intent has altered since month 12, please give details of the previous plan(s) as well.	
hn4_dcf_3a_OngoingPthwy	If the current pathway has been ongoing since the month 12 DCF please tick here and go to question 4.	
hn4_dcf_3_1_DteStrtOfCrrntPln	Please record the date of the MDT or clinic where the decision was made to alter the treatment intent; this will not necessarily be the same as the date of treatment. For example, if the decision were made on 04/04/15 that a patient's pathway was to become palliative, but the patient did not start palliative radiotherapy until 06/07/15 you would record the date of the palliative pathway as 04/04/15. Treatment dates are recorded later in question 7.	hn4_dv_days_frm_cnsnt_to_3_1
hn4_dcf_3_1_DteStrtOfCrrntPlnDteDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_3_1_dtl
hn4_dcf_3b1a_PrvPthwy	If there has been a different pathway before the current one, please record the previous pathways and dates: Previous Pathway 1	
hn4_dcf_3b1b_PrvPthwyDte	Date pathway started:	hn4_dv_days_frm_cnsnt_to_3b1b
hn4_dcf_3b1b_PrvPthwyDteDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_3b1b_dtl
hn4_dcf_3b2a_PrvPthwy	If there has been a different pathway before the current one, please record the previous pathways and dates: Previous Pathway 2	
hn4_dcf_3b2b_PrvPthwyDte	Date pathway started:	hn4_dv_days_frm_cnsnt_to_3b2b
hn4_dcf_3b2b_PrvPthwyDteDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_3b2b_dtl
hn4_dcf_3b3a_PrvPthwy	If there has been a different pathway before the current one, please record the previous pathways and dates: Previous Pathway 3	
hn4_dcf_3b3b_PrvPthwyDte	Date pathway started:	hn4_dv_days_frm_cnsnt_to_3b3b
hn4_dcf_3b3b_PrvPthwyDteDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_3b3b_dtl

5.3.17 Data Capture Form, 3-5 year follow-up (HN4), Section 2 - Recurrence/Residual Tumour/New primaries (4 - 6, 12)

Variable Name	Definition	New Derived Variable Name
hn4_dcf_4_ResidualTumour	Does the patient have any residual head & neck tumour?	
hn4_dcf_5_RcurrTumour	Has the head & neck tumour recurred since month 12?	
hn4_dcf_5a_RcurrStaging_T	If YES, please give the staging of the recurrence: T	
hn4_dcf_5a_RcurrStaging_N	If YES, please give the staging of the recurrence: N	
hn4_dcf_5a_RcurrStaging_M	If YES, please give the staging of the recurrence: M	
hn4_dcf_5a1_RcurrStaging	Staging not recorded	
hn4_dcf_5b_RcurrDteConf	When was the recurrence confirmed?	hn4_dv_days_frm_cnsnt_to_5b
hn4_dcf_5b_RcurrDteConfDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_5b_dtl
hn4_dcf_5c_RcurrLocation	Please give the location of the recurrence	
hn4_dcf_5d_RcurrBfr12m	Did recurrence occur before month 12?	
hn4_dcf_5d1_RcurrBfr12m	Did recurrence occur before month 12 comments	
hn4_dcf_5e_RecNewUnclear	Unclear if it is a recurrence or a new primary	
hn4_dcf_6_1_NwHNPri1	6. Since month 12 has there been a new head & neck primary cancer? Please record any new head and neck primary tumour(s) diagnosed since completion of the Month 12 Data Capture Form. These are head and neck cancers that are not connected to the tumour listed on the Baseline DCF.	
hn4_dcf_6_1a_NwPri1Loc	Location of first new primary (please give as detailed a description as possible e.g.: left floor of mouth)	
hn4_dcf_6_1b_DteDiagMDT	Date diagnosis of first new primary confirmed by MDT	hn4_dv_days_frm_cnsnt_to_6_1b
hn4_dcf_6_1b_DteDiagMDTDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_6_1b_dtl
hn4_dcf_6_1c1_NwPri1Stgng_T	Staging of first new primary : T	
hn4_dcf_6_1c2_NwPri1Stgng_N	Staging of first new primary : N	
hn4_dcf_6_1c3_NwPri1Stgng_M	Staging of first new primary : M	
hn4_dcf_6_1d1_NwPri1ICDCode	ICD code of first new primary	
hn4_dcf_6_1d2_NwPri1ICDCodeSrc	ICD code source of first new primary	
hn4_dcf_6_1d3_NwPri1ICDCodeCmnts	Comments on ICD code of first new primary	
hn4_dcf_6_1e1_NwPri1SNOMED	SNOMED code of first new primary	
hn4_dcf_6_1e2_NwPri1SNOMEDSrc	SNOMED code source of first new primary	
hn4_dcf_6_1e3_NwPri1SNOMEDCmnts	Comments on SNOMED code of first new primary	
hn4_dcf_6_2_NwPri2	Since month 12 has there been a second new primary	
hn4_dcf_6_2a_NwPri2Loc	Location of second new primary (please give as detailed a description as possible e.g.: left floor of mouth)	
hn4_dcf_6_2b_DteDiagMDT	Date diagnosis of second new primary confirmed by MDT	hn4_dv_days_frm_cnsnt_to_6_2b
hn4_dcf_6_2b_DteDiagMDTDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_6_2b_dtl

hn4_dcf_6_2c1_NwPri2Stgng_T	Staging of second new primary : T	
hn4_dcf_6_2c2_NwPri2Stgng_N	Staging of second new primary : N	
hn4_dcf_6_2c3_NwPri2Stgng_M	Staging of second new primary : M	
hn4_dcf_6_2d1_NwPri2ICDCode	ICD code of second new primary	
hn4_dcf_6_2d2_NwPri2ICDCodeSrc	ICD code source of second new primary	
hn4_dcf_6_2d3_NwPri2ICDCodeCmnts	Comments on ICD code of second new primary	
hn4_dcf_6_2e1_NwPri2SNOMED	SNOMED code of second new primary	
hn4_dcf_6_2e2_NwPri2SNOMEDSrc	SNOMED code source of second new primary	
hn4_dcf_6_2e3_NwPri2SNOMEDCmnts	Comments on SNOMED code of second new primary	
hn4_dcf_12a_ResdTumRmnInitHNDg	a. Residual tumour remaining from the initial H&N cancer diagnosis	
hn4_dcf_12b_ResdTumRmnRecHN	b. Residual tumour remaining from recurrence of the H&N cancer	
hn4_dcf_12c_ResdTumRmnNewHN	c. Residual tumour remaining from a new H&N primary cancer	
hn4_dcf_12d_CnsdrdTmrFree	d. Considered to be tumour free from H&N cancer	
hn4_dcf_12e_UnderInvstgtn	e. Is the participant under investigation for a suspicious H&N lesion?	
hn4_dcf_12e1_UnderInvstgtnDesc	*If question 'e' has been answered 'Yes' please give details here:	

5.3.18 Data Capture Form, 3–5 year follow-up (HN4), Section 3 - Treatment since 12 months (7 - 7g)

Variable Name	Definition	New Derived Variable Name
hn4_dcf_7a_SurgSnc12mnths	7a. Surgery since month 12	
hn4_dcf_7b_RadThrpySnc12mnths	7b. Radiotherapy since month 12	
hn4_dcf_7c_ChmBioImmSnc12mnth	7c. Chemotherapy, Biological & Immunotherapy since month 12	
hn4_dcf_7d_HrmnSnc12mnth	7d. Hormone Therapy since month 12	
hn4_dcf_7e_SpPltve	7e. Specialist Palliative (input from the palliative care team for the H&N cancer)	
hn4_dcf_7e1_SpPltveStrtDte	Start Date	hn4_dv_days_frm_cnsnt_to_7e1b
hn4_dcf_7e1_SpPltveStrtDteDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_7e1b_dtl
hn4_dcf_7f1_ActMnHospFU	7f. Active monitoring (Outpatient follow-up) Please tick the answer that applies to the patients Head & Neck cancer follow-up	
hn4_dcf_7f2a_ActMnPatDsch	Nature of follow-up	
hn4_dcf_7f2b_ActMnPtDschDte	Date of letter discharging patient from H&N follow up to GP care	hn4_dv_days_frm_cnsnt_to_7f2b
hn4_dcf_7f2b1_ActMnPtDschDteDtls	Known accuracy of date given.	hn4_dv_days_frm_cnsnt_to_7f2b_dtl
hn4_dcf_7f3a_ActMnOth	Nature of follow-up – Other	
hn4_dcf_7g_Oth	7g. Other (e.g.: radioiodine / blinded drug trial) since month 12	

5.3.19 Data Capture Form, 3-5 year follow-up (HN4), Section 4 - Co-morbidity at 3-5 year follow up (8)

Variable Name	Definition	New Derived Variable Name
hn4_dcf_8b_Cmrb	If the participant has no comorbidities at all, please tick here	
hn4_dcf_8b1_Cmrb_1_Cat	Category	
hn4_dcf_8b2_Cmrb_1_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b3_Cmrb_1_Grade	Grade	
hn4_dcf_8b4_Cmrb_1_Symptm	Symptom	
hn4_dcf_8b5_Cmrb_2_Cat	Category	
hn4_dcf_8b6_Cmrb_2_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b7_Cmrb_2_Grade	Grade	
hn4_dcf_8b8_Cmrb_2_Symptm	Symptom	
hn4_dcf_8b9_Cmrb_3_Cat	Category	
hn4_dcf_8b10_Cmrb_3_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b11_Cmrb_3_Grade	Grade	
hn4_dcf_8b12_Cmrb_3_Symptm	Symptom	
hn4_dcf_8b13_Cmrb_4_Cat	Category	
hn4_dcf_8b14_Cmrb_4_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b15_Cmrb_4_Grade	Grade	
hn4_dcf_8b16_Cmrb_4_Symptm	Symptom	
hn4_dcf_8b17_Cmrb_5_Cat	Category	
hn4_dcf_8b18_Cmrb_5_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b19_Cmrb_5_Grade	Grade	
hn4_dcf_8b20_Cmrb_5_Symptm	Symptom	
hn4_dcf_8b21_Cmrb_6_Cat	Category	
hn4_dcf_8b22_Cmrb_6_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b23_Cmrb_6_Grade	Grade	
hn4_dcf_8b24_Cmrb_6_Symptm	Symptom	
hn4_dcf_8b25_Cmrb_7_Cat	Category	
hn4_dcf_8b26_Cmrb_7_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b27_Cmrb_7_Grade	Grade	
hn4_dcf_8b28_Cmrb_7_Symptm	Symptom	
hn4_dcf_8b29_Cmrb_8_Cat	Category	
hn4_dcf_8b30_Cmrb_8_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b31_Cmrb_8_Grade	Grade	
hn4_dcf_8b32_Cmrb_8_Symptm	Symptom	
hn4_dcf_8b33_Cmrb_9_Cat	Category	
hn4_dcf_8b34_Cmrb_9_CgntAlmnt	Cogent comorbid ailment	

Variable Name	Definition	New Derived Variable Name
hn4_dcf_8b35_Cmrb_9_Grade	Grade	
hn4_dcf_8b36_Cmrb_9_Symptm	Symptom	
hn4_dcf_8b37_Cmrb_10_Cat	Category	
hn4_dcf_8b38_Cmrb_10_CgntAlmnt	Cogent comorbid ailment	
hn4_dcf_8b39_Cmrb_10_Grade	Grade	
hn4_dcf_8b40_Cmrb_10_Symptm	Symptom	

5.3.20 Data Capture Form, 3-5 year follow-up (HN4), Section 5 - Feeding tube/tracheostomy (9 - 11)

Variable Name	Definition	New Derived Variable Name
hn4_dcf_9_FeedingTube	9. Does the patient have a feeding tube?	
hn4_dcf_9a_FeedingTubeIntake	9a. If yes, approximately how much dietary intake is through the feeding tube?	
hn4_dcf_9b_FeedingTubeReason	If the feeding tube has been inserted for a reason not related to the H&N tumour recorded on the Baseline DCF please give the reason for insertion:	
hn4_dcf_10_TempTracheostomy	10. Does the patient have a temporary tracheostomy?	
hn4_dcf_11_PrmLarynStma	11. Does the patient have a permanent laryngeal stoma?	
hn4_dcf_11a_PrmLarynStmaOthReas	If the tracheostomy has been inserted for a condition other than head & neck cancer, please let us know the reason for insertion	

5.3.21 Site reported Mortality Data (Combined from the baseline and follow up Site completed Data Capture Forms. If data was present for both timepoints, data from the earlier timepoint is given)

Variable Name	Definition
mort_1_hndisease	Was death caused by head and neck disease?
mort_2_modedth	Mode of death
mort_3_1a_csedth1	Please record cause of death as reported on the patient's death certificate: 1a
mort_3_1b_csedth2	Please record cause of death as reported on the patient's death certificate: 1b
mort_3_1c_csedth3	Please record cause of death as reported on the patient's death certificate: 1c
mort_3_2_csedth4	Please record cause of death as reported on the patient's death certificate: 2
mort_4_bleed	Did this patient have a catastrophic bleed as a terminal event?
mort_5_airwayobs	Did this patient have an airway obstruction as a terminal event?
mort_6_intervent	Did this patient have any aggressive interventions e.g. emergency tracheostomy in the last 48 hours before their death?
mort_7_sedation	Did this patient receive continuous sedation for the relief of difficult respiratory symptoms at the end of life?
mort_8_placeofdth	Where was the place of death?
mort_8a_placeofdthoth	Where was the place of death? Other, please state
mort_9_careneeds	If the patient did not die at home, was this because their care needs could not be met at home?

5.3.22 Other data

Description	Variable Name	Definition
Index of Multiple Deprivation quintiles	hn1_imd10quint	Quintiles were based on the national cut-points from the 2010 English Index of Multiple Deprivation cut points. Participants were assigned to quintiles according to their postcode.
Year of diagnosis		Year participant was diagnosed by MDT
HPV P16 Status		

5.4 Derived Variable Descriptions

5.4.1 Derived from Questionnaire

Variable Name	Questionnaire Sub-section	Related Variable	Definition	Calculation
dv_ay_height_cm	Section A	ay_a3_Height	Height in centimetres. Heights were given in feet or metres; derived variable standardises the measurements into meters.	*hn1_dv_height_cm = (hn1_a3b_ay_feet_height * 0.3048) + (hn1_a3c_ay_inches_height * 0.0254)*
	Core variables	Height		*Or* *hn1_dv_height_cm = hn1_a3a_ay_cms_height / 100*
dv_ay_weight_kg	Section A	ay_a4_Weight	Weight in kilograms : - Weights were given in stone or Kgs; derived variable standardises the measurements into Kgs.	*hn1_dv_weight_kg = (hn1_a4_b1_ay_stone_weight * 6.3502932) + (hn1_a4_b2_ay_lbs_weight * 0.45359237)*
	Core variables	Weight at baseline		*Or* *hn1_dv_weight_kg = hn1_a4_a_ay_kg_weight*
dv_ay_weight_6mnths_ago_kg	Section A	ay_a4a_Weight6MnthsAgo	Weight 6 months ago in kilograms	*(Same calculation as dv_ay_weight_kg)*
dv_ay_pack_years	Section A	N/A	Smoking pack years : - *12 was used as the minimum age for these calculations. If participants reported starting	Packs = (cigarettes + hand rolled cigarettes) / 20 (*hn1_ay_a11a_TobacUsageCigsDay* + *hn1_ay_a11b_TobacUsageRollDay*) / 20

| | | | smoking before 12, their smoking before 12 was not included in the calculations for this pack-years variable.

Pack-years = 0 for never smokers.

• Participants are defined here as never, former or current smokers based on their response to *hn1_ay_a8_Tobac*.
• Questions on other forms of tobacco (*hn1_ay_a11c_TobacUsagePipeDay*, *hn1_ay_a11d_TobacUsageSmklssDay*) were ignored when calculating pack-years.
• Participants were coded as missing if they were current or former smokers and reported smoking zero cigarettes. (2 participants) | Duration (for current smokers) = age at consent – age started smoking*
hn1_dv_age_cons –
hn1_ay_a10_TobacUseAgeStart |
| | | | • If participants gave data that resulted in a duration of zero or a negative value close to zero (minimum -3), duration was recoded to 1 year. For example, someone who is 45 years old might report starting smoking at 20 and quitting 25 years ago. (12 participants)
• Otherwise, participants that gave data that resulted in a negative duration were coded as missing. (5 participants)
• If never smokers also provided data on cigarettes and duration, pack-years were calculated for these participants. (15 participants)
• If current smokers also provided data on years since quitting, the response for years since quitting was | Duration (for former smokers) = (age at consent – years since quitting) – age started smoking*
(hn1_dv_age_cons –
hn1_ay_a9_TobacHowLngStopYrs) –
hn1_ay_a10_TobacUseAgeStart |

			ignored and duration was calculated as for current smokers. (5 participants) If participants with missing data for *hn1_a8_ay_tobacco* also provided data on cigarettes and duration, pack-years were calculated for these participants. (24 participants)	
dv_ay_drink_ever	Section A	N/A	Is participant a current alcohol consumer?	hn1_dv_drink_ever = 0 if hn1_ay_a13a_drink_days = 0 or hn1_a13b_ay_drink_days = 1 Or hn1_dv_drink_ever = 1 if hn1_ay_a13a_drink_days ≥ 1 and ≤ 7
dv_ay_drink_days	Section A	N/A	Number of days per week alcohol consumed.	hn1_dv_drink_days = hn1_ay_a13a_drink_days Or hn1_dv_drink_days = 0 if hn1_ay_a13a_drink_days = 0 or hn1_a13b_ay_drink_days = 1
dv_ay_units_per_wk	Section A	N/A	Total weekly alcohol consumption (units)	*Responses to hn1_a15a_ay_wine_pw, hn1_a15b_ay_spirits_pw and*

				hn1_a15c_ay_pints_pw were converted to the values shown in *Figure A.* below and then summed to calculate total units per week.
dv_ay_hhold_income	Section A	ay_a21_IncmHholdTotal	Total annual household income from all sources before tax and other deductions Income was given in weekly or annual figures. Standardised so that all figures are annual.	
dv_eortc_c30_phys_func dv_eortc_c30_role_func dv_eortc_c30_emot_func dv_eortc_c30_cog_func dv_eortc_c30_soc_func dv_eortc_c30_gnrlhlthscr dv_eortc_c30_fatigue dv_eortc_c30_nausea dv_eortc_c30_pain dv_eortc_c30_dyspnoea dv_eortc_c30_insomnia dv_eortc_c30_appetite dv_eortc_c30_constipation dv_eortc_c30_diarrhoea dv_eortc_c30_financial	Section C EORTC qlq-C30 scoring		EORTC qlq-C30 scoring (currently not completed for the follow-up study).	
dv_days_frm_cnsnt_to_d54a1b	Section D (hn4 only)	sayh_d54a1b_DteOfDiagn	*Days from consent to date of diagnosis of previous cancer (d54a1b)*	*Date of consent - Date given in d54a1b*
dv_days_frm_cnsnt_to_d54a2b	Section D (hn4 only)	sayh_d54a2b_DteOfDiagn	*Days from consent to date of diagnosis of previous cancer (d54a2b)*	*Date of consent - Date given in d54a2b*
dv_days_frm_cnsnt_to_d54a3b	Section D (hn4 only)	sayh_d54a3b_DteOfDiagn	*Days from consent to date of diagnosis of previous cancer (d54a3b)*	*Date of consent - Date given in d54a3b*
dv_days_frm_cnsnt_to_d54a4b	Section D (hn4 only)	sayh_d54a4b_DteOfDiagn	*Days from consent to date of diagnosis of previous cancer (d54a4b)*	*Date of consent - Date given in d54a4b*
dv_days_frm_cnsnt_to_d54a5b	Section D (hn4 only)	sayh_d54a5b_DteOfDiagn	*Days from consent to date of diagnosis of previous cancer (d54a5b)*	*Date of consent - Date given in d54a5b*
dv_hads_anx_scr dv_hads_dprsn_scr	Section E HADS Scoring	N/A	**HADS Scoring detailed in Figure B. below.** **Scoring:**	

dv_hads_anx_scr_grp_txt			**Total score: Depression (D) or Anxiety (A)** 0-7 = Normal 8-10 = Borderline abnormal (borderline case) 11-21 = Abnormal (case)	
dv_hads_dprsn_scr_grp_txt				
dv_days_frm_cnsnt_to_dcf	DCF	dcf_a1a_DteDataCllctn	Days from consent to data collection *Baseline site reported Data Capture Form was completed at baseline in clinic, so no data is given for this timepoint.*	*Date of consent – Date of data*
dv_days_frm_cnsnt_to_q	Section A	ay_a1_Date	Days from consent to data collection	*Date of consent – Date of data*
dv_age_at_cnsnt	Section A	ay_a2_DateOfBirth	Age at date of consent to nearest year	*Date of consent - Date of birth*
	DCF	dcf_a2_DOB		
	Core variables	dv_age_at_cnsnt		
dv_days_frm_cnsnt_to_ref	DCF	dcf_a3_DteOfRefrrl	Days from consent to referral	*Date of referral - Date of consent*
dv_days_frm_cnsnt_to_diag	DCF	dcf_a4_DteOfDiagn	Days from consent to date of diagnosis	*Date of diagnosis - Date of consent*
dv_days_frm_ref_to_diag	DCF	dcf_a4_DteOfDiagn	Days from referral to diagnosis	*Date of diagnosis - Date of referral*
dv_days_frm_cnsnt_to_mdt	DCF	dcf_a7_MDTDte	Days from consent to MDT decision date	*Date of MDT decision - Date of consent*
dv_days_frm_ref_to_mdt	DCF	dcf_a7_MDTDte	Days from referral to MDT treatment decision	*Date of MDT treatment decision - Date of referral*
dv_days_frm_cnsnt_to_dth	DCF	dcf_a11_DtOfDth	Days from consent to death	*Date of death – Date of consent*
		dcf_2a_DtOfDth		
dv_days_frm_cnsnt_to_prcd_st	DCF	dcf_b10_StartDte	Days from consent to Procedure/Treatment start date	*Procedure/Treatment start date – Date of consent*
dv_sex	DCF	dcf_a8_Sex	Participants sex, collated and checked from all sources we have	
	Core variables	Gender		
dv_ethnicity_txt	DCF	dcf_a9_Ethnicity	Ethnicity, collated and checked from all sources we have	
	Core variables	Ethnicity		

Figure A.

Alcohol Units

Bottles of wine		*Bottles of spirits*		*Pints of beer/lager/cider*	
None	0	None	0	None	0
Less than 1	4.5	Less than 1	13.5	Less than 1	7
1	9	1	27	1	21
2-3	22.5	2-3	67.5	2-3	36
4-6	44	4-6	135	4-6	50
7-10	76.5	7-10	229.5	7-10	63
11 or more	99	11 or more	297	11 or more	72

Figure B.

Hospital Anxiety and Depression Scale (HADS)
Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions
Scoring:
Total score: Depression (D) or Anxiety (A)
0-7 = Normal   8-10 = Borderline abnormal (borderline case)   11-21 = Abnormal

5.4.2 Tumour Data

Description	Variable Name	Definition
Clinical ICD code	hn1_dv_icd_code_clin	Clinical ICD code (from site completed DCF)
Clinical ICD code group	hn1_dv_icd_group_clin	Clinical ICD code (from site completed DCF) group. ICD codes were grouped as based on the AJCC Cancer Staging Manual v7.
Pathological ICD code	hn1_dv_icd_code_path	ICD Code as given on pathology report
Pathological ICD code group	hn1_dv_icd_group_path	Group of ICD code as given on pathology report
Combined ICD code	hn1_dv_icd_code_comb	This variable used ICD codes from pathology reports where available. Where the pathology ICD code was missing, the ICD code from the clinical notes (*hn1_na5a_cb_primary_icd*) was used.
Combined ICD code group	hn1_dv_icd_group_comb	This variable used ICD codes from pathology reports where available. Where the pathology ICD code was missing, the ICD code from the clinical notes (*hn1_na5a_cb_primary_icd*) was used.
Confirmed ICD code with salivary grouped	hn1_dv_icd_group_conf	To create the final variable presented here (*hn1_ICD_group_conf*), tumours identified as salivary gland based on pathology reports but not included in the salivary glands group were recoded as minor salivary gland tumours and then combined with major salivary gland tumours.
Clinical stage	hn1_dv_tnm_stage_clin	Clinical Tumour staging, based on the AJCC Cancer Staging Manual v7. This variable used ICD codes from pathology reports where available. Where the pathology ICD code was missing, the ICD code from the clinical notes (*hn1_na5a_cb_primary_icd*) was used.
Best TNM T	hn1_dv_tnm_t_best	TNM staging is categorised according to the TNM Classification of Malignant Tumours, Seventh Edition
Best TNM N	hn1_dv_tnm_n_best	(Wittekind et al., 2009 [ref]).
Best TNM M	hn1_dv_tnm_m_best	The following recodes were applied to the T, N, M variables in order to create this final TNM staging variable: ***dcf_b5b_RecentTNM_t*** Recoded to 1: 1/2, 1a, 1b, 1m. Recoded to 2: 2a, 2b. Recoded to 3: 3/4. ***dcf_b5c_RecentTNM_n*** Recoded to 1: 1a, 1b, 1m. Recoded to 3: 3a, 3b. ***dcf_b5d_RecentTNM_m*** Recoded to 0: 0/1. Recoded to missing: x. *For thyroid cancer only, recoded to missing: 2b
Best stage	hn1_dv_tnm_stage_best	Clinical Tumour staging, based on the AJCC Cancer Staging Manual v7.
SNOMED Code grouping	hn1_dv_snomed_group	SNOMED codes grouped as follows: 1 - M8070/3 = Squamous carcinoma (Not otherwise specified) 2 - M8071/3 = Keratinising squamous carcinoma

		3 - M8072/3 = Non-keratinising squamous carcinoma
Treatment group - Planned	hn1_dv_tx_planned_group	Laser surgery (*hn1_nb2m_cb_laser_surg*) was considered equivalent to primary surgery
Treatment group - Actual	hn2_dv_tx_actual_group	(*hn1_nb2a_cb_surg_primary*). Biological treatment (*hn1_nb2h_cb_biological*) was considered equivalent to chemotherapy (*hn1_nb2d_cb_chemother*). A new variable was created for radiotherapy. Participants received radiotherapy if they received teletherapy (*hn1_nb2c_cb_telether*) or brachytherapy (*hn1_nb2g_cb_brachyther*). Two variables were created to classify participants according to what kind of surgery they received and what kind of chemotherapy and/or radiotherapy they received. The categories were: **Surgery** 1 - No surgery 2 - Primary surgery without neck surgery 3 - Primary surgery and neck surgery 4 - Other surgery (neck surgery or reconstructive surgery) **Chemotherapy and/or radiotherapy** 1 - None 2 - Radiotherapy only 3 - Chemotherapy only 4 - Chemoradiotherapy, chemotherapy and radiotherapy These two variables were combined to create the treatment groups.

5.4.3 Other Data

Description	Variable Name	Definition
Was participant alive at censoring date?	hn1_dv_vital_status	Vital status was taken from multiple sources, including site reported and NHS digital death data.
Days from consent to censoring or death	hn1_dv_days_frm_cnsnt_to_censdth	This variable shows the number of days between consent and the last date we had an update on any participants vital status or, if the participant is deceased (as denoted in the hn1_dv_vital_status) the number of days between consent and the date of death.