Data catalogue of the Netherlands Quality of Life and Biomedical Cohort Study on head and neck cancer (NET-QUBIC)

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A. Introduction

Research over the past decades provided convincing evidence that cancer patients and their informal caregivers have to deal with various physical, psycho-behavioural and social side effects of cancer and cancer treatment, negatively affecting quality of life (QoL). Particularly in understudied cancer populations such as head and neck cancer (HNC), little is known about the course of QoL, and its determinants across the disease-span. In addition, there is limited insight in the prognostic value of QoL on survival. This association can be influenced by various cancer-related, personal, biological, psycho-behavioural, lifestyle-related and social factors. Comprehensive insight in all these factors, assessed in a standardized manner is necessary to unravel these complex associations.

The primary objective of NET-QUBIC is to describe the long term course of QoL in newly-diagnosed cancer patients and their informal caregivers and to identify cancer-related, personal, biological, psycho-behavioural, physical, lifestyle-related, and social determinants of QoL.

Secondary aims are

- to investigate the association between QoL and survival in cancer patients, taking into account broadly defined cancer-related, personal, biological, psycho-behavioural, lifestyle-related, and social determinants;
- to build predictive models for long term QoL and survival of cancer patients;
- to determine whether the association between QoL and survival is direct or mediated by cancer-related, personal, biological, psycho-behavioural, lifestyle-related, and social factors;
- to prospectively examine supportive care needs of patients and caregivers in all phases of the disease (from diagnosis to the terminal phase), and the association with the long-term course of QoL.

NET-QUBIC is a longitudinal observational cohort study, following up on cancer patients and caregivers over 5 years. In total 739 patients and 262 caregivers are included. These patients and caregivers were recruited from 5 University Medical Centers in The Netherlands in Amsterdam, Groningen, Nijmegen, Utrecht, and Rotterdam and regional hospitals in Alkmaar and Leeuwarden.

Assessments will take place before the start of primary cancer treatment which is approximately 3 weeks after diagnosis (baseline), and at 3 and 6 months, and 1, 2, 3, 4 and 5 years after treatment. Data is collected via patient reported outcomes, face-to-face interviews, medical examinations, and biological samples.

The study protocol has been approved by the medical ethical committee of VUmc (2013.301(A2020.388)-NL45051.029.13) and all local participating centers. The biobank protocol has also been approved by the biobank committee of VUmc (2018.406). All patients and caregivers signed informed consent at baseline. In addition, (part of the) patients signed informed consent for the additional home visit and biobank sample collection at 5 years follow-up. More information on the NET-QUBIC project can be found in the design paper of Verdonck-de Leeuw et al. (2019) [1], the feasibility study of van Nieuwenhuizen et al. (2014) [2] and the study on retention rates up to 2 years follow-up of Jansen et al. [3].

The NET-QUBIC Datawarehouse and Biobank are open for collaboration with (inter)national researchers. New data releases will be organized once or twice a year and will be announced on the NET-QUBIC website (www.kubusproject.nl). Usage of NET-QUBIC data and/or biomaterials is regulated in the NET-QUBIC Data and Biomaterial Access Policy, and in the NET-QUBIC Publication policy (more information can be found on the website).

The aim of this document is to provide detailed background information on the NET-QUBIC Data Warehouse.

B. Coding NET-QUBIC Data Warehouse

To provide researchers tailored access to all clinical data, patient-reported outcome measures, objective tests and biobank assay results are saved as an individual zipped data file per time point.

Each zipped file has a number, for example NQ_x110 for EORTC QLQ-C30 data, in which x indicates the time point of measurement, namely:

A = Baseline

B = 3 months follow-up (i.e. after end of treatment)

C = 6 months follow-up (i.e. after end of treatment)

D = 1 year follow-up (i.e. after end of treatment)

E = 2 years follow-up (i.e. after end of treatment)

F = 3 years follow-up (i.e. after end of treatment)

G = 4 years follow-up (i.e. after end of treatment)

H = 5 years follow-up (i.e. after end of treatment)

File NQ_A110 thus contains baseline EORTC QLQ-C30 data. Every variable within a zipped file also starts with this wave number (e.g. aeortcc01, aeortcc02, …)

Within one zipped file four file types can be distinguished, namely:

1. R-syntax: SPSS syntax raw data (only available upon request)
2. R-file: SPSS datafile with raw data (i.e. individual items, such as aeortcc01)
3. D-syntax: SPSS syntax derived data (if applicable)
4. D-file SPSS datafile with derived data (e.g. domain scores as aeortcc_pf) (if applicable)

The last letter of the datafile name indicates the type of file, thus NQ_A110R.sav and NQ_A110R.sps are the baseline raw data file and syntax of the EORTC QLQ-C30. NQ_A110D.sav and NQ_A110D.sps are the baseline derived data file and syntax.

Data files of caregivers have an additional character, namely an ‘n’. NQ_A110Dn.sav is thus the baseline derived data file of the EORTC QLQ-C30 of caregivers.

C. Clinical information and flow diagram

NQ_x401 eCRF Clinical data (baseline) (patients only)

An electronic case report form (eCRF) was completed by trained researchers/MDs or field workers based on the medical files at baseline (NQ_A401), at 2 years after the end of treatment (NQ_E401), and at 5 years after the end of treatment (NQ_H401) using Open Clinica and Castor software.

Baseline eCRF (NQ_A401)

The baseline eCRF contains general sociodemographic and clinical information as well as tumour characteristics, detailed treatment information, and pathology data. General sociodemographic and clinica; information collected include incidence date, age, sex, WHO performance [4, 5], performed diagnostics, ACE-27 comorbidity score [6], and weight loss prior to treatment (grams).

Tumour characteristics include tumour site (ICD-10), tumour lateralisation, lymph node and distant metastasis, and TNM 7 classification (2010).

Information on treatment encompasses a question on type of treatment, followed by more detailed questions per treatment option. For surgery, more detailed information on type of surgery, surgery reconstruction, neck surgery (including details about removed levels and nonlymphatic structures), histologically radicality of the primary tumour, extended morphology of the tumour, degree of differentiation, number of nodes removed, number of positive nodes, extranodal spread, and pathological TNM 7 classification (2010) tumour and lymph node metastasis, and pathological TNM 7 classification (2010) was collected.

For radiotherapy, information on type of radiotherapy (primary, postoperative or other), used technique, used boost technology, and start and end date of radiotherapy was collected. In addition, for patients treated with primary radiotherapy, information on total dose primary tumor and N+ (Gray), fraction dose primary tumor and N+ (Gray), fractions per week primary tumor and N+, total dose elective lymph nodes (Gray), fraction dose elective lymph nodes (Gray), fractions per week elective lymph nodes (Gray), and radiotherapy duration elective lymph nodes was collected. For patients treated with postoperative radiotherapy, information on total dose high risk areas (Gray), fraction dose high risk areas (Gray), fractions per week high risk areas, radiotherapy duration high risk areas, total dose intermediate risk areas (Gray), fraction dose intermediate risk areas (Gray), fractions per week intermediate risk areas, radiotherapy duration intermediate risk areas, total dose elective lymph nodes (Gray), fraction dose elective lymph nodes (Gray), fractions per week elective lymph nodes, and radiotherapy duration elective lymph nodes was collected.

For chemotherapy, information on type of chemotherapy (induction, concomitant, concomitant bioradiation, postoperative chemotherapy, or other), type of cytostatic, chemotherapy scheme, completion of chemotherapy or reason for non-completion, start date, final dose (mg/m^2), and information on adverse events was collected.

Pathology data collected include HPV status, type of HPV test, and relevant PA numbers.

Two years and five years follow-up eCRF (NQ_E401 and NQ_H401)

The two an five years follow-up eCRF contains information on delirium (2 years follow-up only), residual tumor (2 years follow-up only), tumor recurrence, diagnosis of a second primary tumor and mortality within the two or two to five year follow-up period. In case a residual tumor, recurrence or second primary tumor was diagnosed follow-up questions are completed that address date of diagnosis, location, treatment and treatment intent. In case a patient died, data of death was registered as well as relation of death with the tumor (i.e. death with disease (cancer) or death other cause)). In case the vital status of the patient was unknown due to drop-out, transfer to another hospital and/or dismissal from follow-up care, vital status was requested from the municipal basis administration. Vital status was known in 99% of the patients. In case vital status was unknown data of censoring was provided (for survival analyses) in NQ_H401.

NQ_x402 Flow diagram

The flow diagram file was completed after all 2-years follow-up data was collected and after all 5 years follow-up data was collected. For more information on the NET-QUBIC flow diagram up to 2 years follow-up, see Jansen et al. [3]. This data file provides information on drop-out, missing data at a certain time point and mortality. Patients/caregivers were coded as 'drop-out' in case no further data was available on **all** components (PROMs, interview, biobank) at **all** further time points. In case data was missing but data was available on other components (for example PROMs were missing, but interview data was available) or beyond this certain time point, the patient/caregiver was coded as 'having missing data' (and not as drop-out). Researchers who use the NET-QUBIC data should in case specific data is missing but the patient/caregiver has not 'dropped-out' yet also state that data is missing (and not that the patient/caregiver dropped-out).

Patients/caregivers were coded as 'drop-out: patient/caregiver died' in case they died while still participating in the study. The total number of patients/caregivers who died is higher as some patients/caregivers dropped out due to other reasons before they died. In the group of caregivers we are not aware of dead after drop-out. In the group of patients this information is collected as part of the two-years follow-up eCRF. Using this data the total number of patients still alive per time point are

coded into the variables “Died_M3; Died_M6, …”, as also presented on the next page as the total number of patients still alive in the blue boxes.

In case the patient died, the caregiver was asked to complete a selection of the caregiver-reported outcome measures and an additional caregiver-reported outcome measure on grief one last time, see section H. Data of this measurement is not part of the ‘regular’ data files of caregivers. In case the patient dropped-out of the study the caregiver automatically also dropped-out.

NQ_x403 Informed consent (not eligible for data release)

All 739 patients and 262 caregivers signed informed consent at baseline. All patients still participating at 5 years follow-up were again asked for their informed consent on the additional home visit and biobank sample collection at 5 years follow-up. In addition to the overall informed consent statement patients and caregivers were asked for their informed consent on 5 sub-topics, namely (1) consent to inform the patient’s general practitioner on blood results, (2) consent to merge results of the NET-QUBIC study with other registration systems, (3) consent to store body materials for up to 25 years, (4) consent to take blood samples for DNA/RNA research, and (5) consent to be informed on hereditary characteristics. Also, at 5 years, patients were asked for their approval to audio record the home visit and to approach them in the future for other research. This data file provides information on the specific informed consent per sub-topic.

NQ_x404 Interval incidence date and start treatment

This datafile provides information on number of days between incidence date and start of treatment. The data was provided by the Netherlands Comprehensive Cancer Organisation (IKNL) in December 2022. For incidence date often the date of biopsy was used. The information is only available for n=729, as 10 patients did not provide informed consent to link their data to other databases. The data is only provided in case of IKNL approval.

D. Patient/caregiver-reported outcome measures (one-time)

In patients, information on education and literacy and country of birth were assessed once during the fieldwork interview at baseline. In case no interview was performed at baseline, these patient-reported outcome measures were collected at follow-up together with the other patient-reported outcome measures. All other one-time questionnaires were part of the patient-reported outcome booklet assessed at baseline. In case this booklet was not completed at baseline, patients were asked to complete these one-time only questions as part of the follow-up assessment.

In caregivers, information on education and literacy and country of birth were assessed together with all other one-time questionnaires (except caregiver type) as part of the baseline caregiver-reported outcome booklet.

NQ_x101 Demographics (caregivers only)

This datafile contains information on age and gender of caregivers. Age and gender of patients can be found in the baseline eCRF file (NQ_A401).

NQ_x103 Education and literacy

Education and literacy were measured using a 7-item study-specific questionnaire. This study-specific questionnaire contained questions on highest educational degree (1 item), perceived skills in the Dutch language (2 items) and perceived health literacy (4 items).

NQ_x104 Country of birth and family

Information on country of birth and family were measured using an 8-item study-specific questionnaire. This study-specific questionnaire included questions on country of birth, nationality, the parents' country of birth and the grandparents' country of birth. In addition, it encompassed information on living situation, marital status, having children and having siblings. Also, history of cancer in the family (children, parents and siblings) and the participants own history of cancer was assessed.

Remark: the current online version is a 'light' version of this questionnaire, as the total file encompasses potential identifying information as date of marriage or country of birth.

NQ_x105 Diseases – Self-administered Comorbidity questionnaire (SCQ) (caregivers only)

Data on comorbidity among caregivers was collected using the self-administered comorbidity questionnaire (SCQ). This questionnaire has previously been validated in Dutch by Stolwijk et al. among patients with ankylosing spondylitis [7].

NQ_x112 Personality (big five) - NEO Five Factor Inventory (NEO-FFI)

Personality was measured with the 60-item NEO Five Factor Inventory (NEO-FFI) measuring neuroticism (12 items), extraversion (12 items), agreeableness (12 items), conscientiousness (12 items), and openness to experience (12 items) [8]. All questions are answered on a 5-point Likert Scale ranging from strongly disagree (1 point) to strongly agree (5 points).

For each of the five personality characteristics a sum score was calculated ranging from 12 to 60. A higher score on each of the domains indicates a higher level of neuroticism, extraversion, agreeableness, conscientiousness or openness to experience.

In this dataset, missing data was imputed by the mean score of the other items of the particular scale in case at least 9 of the 12 items within the scale were answered. For some research questions, however, other methods for data imputation may be more appropriate. In that case R data files can be used which contains data on item level.

Psychometric properties of the Dutch version of the NEO-FFI have been reported to be satisfactorily [9].

NQ_x113 Locus of control - Pearlin Schooler and Mastery Scale (PSMS)

Locus of control was assessed by the 7-item Pearlin Schooler and Mastery Scale (PSMS), examining the degree to which persons consider their own life changes to be under their own control rather than determined by fate [10, 11].

Based on the items both a 7-item mastery total scale score and an abbreviated 5-item mastery total scale score was calculated. The 5-item total scale score ranges from 5 to 25 and the 7-item total scale score ranges from 7 to 35. A higher score indicates more feelings of mastery.

In this dataset, missing data was imputed by the mean score of the other items in case maximal one of the items was missing. For some research questions, however, other methods for data imputation may be more appropriate. In that case R data files can be used which contains data on item level.

To our knowledge psychometric characteristics have not yet been assessed in a Dutch (cancer) population.

NQ_x115 Coping - Utrecht Coping List (UCL)

Coping behaviour was assessed by the 47-item Utrecht Coping List (UCL): active coping (7 items), palliative coping (8 items), avoidance coping (8 items), seeking support (6 items), passive coping (7 items), expression of emotions (3 items), and comforting thoughts (5 items) and three single items [12]. All items refer to a general situation.

For each of the subscales a sum score was calculated. A higher score indicates more active coping, palliative coping, avoidance coping, seeking support, passive coping, expression of emotions, and comforting thoughts. A total score was calculated in case at least 4 out of 5 items of a domain were completed.

The Utrecht Coping List is a reliable and valid measurement instrument [13, 14].

NQ_x116 Social desirability

Social desirability was measured using a 5-item study-specific questionnaire, which has previously been used in the Longitudinal Aging Study Amsterdam (LASA) [15]. All items refer to a general situation. This questionnaire can be used to obtain insight in whether subjects have the tendency to respond in a socially desirable manner to attitudinal questionnaires.

NQ_x127 Fertility

Fertility in women was assessed with a study-specific questionnaire. This questionnaire contains questions on menstrual status before, during, and after treatment, age at menopause, number of children before and after treatment, hormone replacement therapy (HRT), and the use of anti-conception.

NQ_x132 Caregiver type

This datafile provides information on the relation type between the patient and caregiver. This information was filled in retrospectively by the fieldworker.

E. Patient/caregiver-reported outcome measures (questionnaire A)

These patient/caregiver-reported outcome measures were completed by the patient/caregiver as part of questionnaire booklet A before start of treatment and at 3 and 6 months, and 1, 2, 3, 4 and 5 years after the end of treatment.

NQ_x102 Weight

Current weight (kg) and weight two years ago were measured by self-report.

Remark: A few patients have a strange change in weight over time (e.g. more than 100 kg change), we checked the data with the paper versions of the questionnaire and it was the actual data.

NQ_x106 Smoking and nicotine dependence

A 13-item study-specific patient-reported questionnaire was used to assess smoking status and nicotine dependence. The questionnaire included questions on passive smoking (1 item), smoking behaviour (including smoking history) (7 items) and nicotine dependence (5 items). Based on the items, patient were categorized in the outcome variable current smoker (yes/no) in which patients who were current smokers were categorized into yes and patients who never smoked (i.e. less than 100 units in their lifetime) or stopped smoking (daily) were categorized into no.

NQ_x107 Alcohol intake and dependence

A 21-item study-specific questionnaire was used to assess alcohol intake and dependence, consisting of questions on current alcohol intake and history of alcohol intake (14 items) and alcohol dependence (7 items).

Based on the items, patient were categorized in the outcome variable excessive alcohol consumption (yes/no) according to the definition of excessive drinking of the National Institute for Public Health and the Environment (RIVM) [16]. Patients who drank more than 14 (women) or 21 (men) glasses of alcohol per week were coded into yes (i.e. excessive alcohol consumption), whereas patients who drank 14 glasses (women) or less or 21 glasses or less (men) were coded into no (i.e. no excessive alcohol consumption).

NQ_x108 Drugs use

An 8-item study-specific questionnaire was used to measure (history of) drug use, including use of Cannabis, XTC, speed, cocaine, GHB, LSD and other drugs.

NQ_x109 Generic quality of life - EuroQol (EQ-5D + VAS)

Generic quality of life was measured using the EuroQol-5D (EQ-5D). The EQ-5D consists of five items measuring current problems on five dimensions of quality of life (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). Participants can answer they have no problems, some problems or extreme problems. In addition, patients were asked to rate their health on a visual analogue scale ranging from 0 to 100, in which 100 indicates the best imaginable health state [17].

Based on the five dimensions of quality of life an EQ-5D utility score (range from -.33 to 1.00) was calculated in which a higher score indicates a better quality of life. The total EQ5D utility score provided in this dataset is calculated using the Dutch index tariff [17]. No assumptions were made regarding missing data.

The EQ-5D is a reliable and valid measurement instrument for use in cancer patients [18].

NQ_x110 Disease-specific quality of life - EORTC QLQ-C30

The 30-item EORTC QLQ-C30 (version 3.0) includes a global health-related quality of life scale (2 items) and comprises five functional scales: physical functioning (5 items), role functioning (2 items), emotional functioning (4 items), neurocognitive functioning (2 items) and social functioning (2 items). There are three symptom scales: nausea and vomiting (2 items), fatigue (3 items) and pain (2 items), and 6 single items relating to dyspnoea, insomnia, loss of appetite, constipation, diarrhoea and financial difficulties [19, 20]. All items, except for the items on physical functioning, refer to the last week. The items on physical functioning are general items.

All scales and single items were converted to a score from 0 to 100. A higher score on the functioning scales or the global quality of life scale represents a better quality of life, whereas a higher score on the symptom scales or the single items indicate a higher level of symptoms. Also, a total summary score was calculated ranging from 0 to 100 including 27 of the 30 items, as described by Giesingen et al. [21], in which a higher score indicates a better quality of life.

In this dataset, for functioning and scale scores, missing data was imputed by the mean score of the other items of the particular scale in case at least half of the other items within the scale were answered, as also suggested in the EORTC manual [22]. These functioning and scale scores were consequently used to calculate the total sum score, no further assumptions were made. For some research questions, however, other methods for data imputation may be more appropriate. In that case, data on the item level should be used, which does not contain imputed data.

The EORTC QLQ-C30 is developed in a cross-cultural setting and is a valid and reliable instrument for quality of life assessments in various cancer populations [19, 20].

NQ_x111 Tumour-specific quality of life - EORTC QLQ-HN35 (patients only)

The EORTC QLQ-HN35 module covers specific health-related quality of life issues on head and neck cancer. The questionnaire comprises seven subscales: pain (4 items), swallowing (5 items), senses (2 items), speech (3 items), social eating (4 items), social contact (5 items) and sexuality (2 items). There are six symptom items (covering problems with teeth, dry mouth, sticky saliva, cough, feeling ill, opening the mouth wide) and five single items (weight loss, weight gain, use of nutritional supplements, feeding tubes, and painkillers) [23]. All items, refer to the last week.

All scales and single items range in score from 0 to 100, higher scores indicate a higher level of symptoms.

In this dataset, for scale scores, missing data was imputed by the mean score of the other items of the particular scale in case at least half of the other items within the scale were answered, as also suggested in the EORTC manual [22]. For some research questions, however, other methods for data imputation may be more appropriate. In that case data on item level can be used, which does not contain imputed data.

The EORTC QLQ-HN35 is developed in a cross-cultural setting and is a valid and reliable instrument for quality of life assessments in head and neck cancer patients [24].

NQ_x114 Coping - Mental Adjustment to Cancer (MAC) (patients only)

Cognitive and behavioural response to cancer diagnosis and treatment was assessed by the 40-item Mental Adjustment to Cancer (MAC) questionnaire. The MAC scale comprises five subscales: fighting spirit (16 items), helplessness/hopelessness (6 items), anxious preoccupation (9 items), fatalism (8 items) and avoidance (1 item) [25]. All items refer to the current situation.

On each of these five subscales a sum score was calculated. A higher score indicates more fighting spirit, helplessness/hopelessness, anxious preoccupation, fatalism or more avoidance. Besides, based on these five sum scores, two summary scores can be calculated, namely positive adjustment (17 items) and negative adjustment (16 items). A total score was calculated in case at least 4 out of 5 items of a domain were completed.

Psychometric characteristics of the MAC have previously been investigated among mixed cancer patients, including Dutch cancer patients [26, 27].

NQ_x117 Severity anxiety/depression - Hospital Anxiety and Depression Scale (HADS)

A validated Dutch version of the Hospital Anxiety and Depression Scale (HADS) was used to assess the level of anxiety and depression symptoms. The HADS is a 14-item patient-reported outcome measure for measuring distress (total HADS score) with two subscales, anxiety (HADS-A) and depression (HADS-D) [28]. The HADS was specifically designed for use in the medically ill. All items refer to the last week.

The total HADS score ranges from 0 to 42, the subscales from 0 to 21. A higher score on the total scale and on the subscales indicates higher levels of distress, anxiety or depression. No assumptions were made regarding missing data. A total HADS score of >14 is used as an indicator for a high level of psychological distress [29].

The HADS is a valid instrument for use in Dutch persons [28].

Remark: The patient (Spinhoven) and caregiver (Bonke&Serlie) version of the HADS differ.

Remark: The patients from ErasmusMC completed the Bonke&Serlie version instead of the Spinhoven version.

NQ_x118 Fatigue - Multidimensional Fatigue Inventory (MFI)

Fatigue was assessed using the 20-item Multidimensional Fatigue Inventory (MFI): general fatigue (4 items), physical fatigue (4 items), reduced activity (4 items), reduced motivation (4 items) and mental fatigue (4 items) [30-32]. All items refer to the last few days.

Total score per domain ranges from 4 to 20, in which a higher score indicates a higher level of fatigue. Calculating a total sum score including all 20 items is not recommended, since the separate dimensions of fatigue are expected not to contribute equally to the global judgement on fatigue. If, one is interested in just one score as an indicator of fatigue, usage of the general fatigue score is recommended by the user manual [33]. No assumptions were made regarding missing data.

The MFI is a valid instrument for use in a heterogeneous Dutch group of cancer patients treated with radiotherapy and individuals participating in a study on the chronic fatigue syndrome [32].

NQ_x119 Swallowing - Swallowing Quality of Life Questionnaire (SwalQoL) (patients only)

The SwalQoL is a 47-item patient-reported outcome measure that consists of ten different quality of life domains namely food selection (2 items), eating duration (2 items), eating desire (3 items), fear (4 items), burden (2 items), mental health (5 items), social functioning (5 items), communication (2 items), sleep (2 items) and fatigue (3 items). Furthermore, a symptom scale (14 items) is included. Based on the 23-items of the first seven mentioned quality of life domains a total SwalQoL score can be calculated. Finally, three separate questions on nutrition intake (normal, soft, pureed, mostly tube feeding, only liquids, tube feeding solely), liquids intake (all liquids, thick liquids, very thick liquids, thickened liquids, no liquids), and general health (poor, moderate, good, very good, excellent) are included. All items refer to the last month. For this study the subscales communication, sleep and fatigue were removed, because of considerable overlap with the Speech Handicap Index and the Multidimensional Fatigue Inventory.

All SwalQoL scales range in score from 0 to 100, a higher score indicates more impairment. Missing data on the different SwalQol scales were imputed by the mean score of the other items of

the particular scale in case less than 50% was missing. For some research questions, however, other methods for data imputation may be more appropriate. In that case, data on item level can be used, which does not contain imputed data.

The SwalQol has been translated into Dutch and validated for use in patients with head and neck cancer [34] and laryngeal cancer [35].

NQ_x120 Speech - Speech Handicap Index (SHI) (patients only)

The Speech Handicap Index (SHI) is a 31-item patient reported outcome measure on speech problems in daily life. Response categories range on a five point scale (never (0 points), almost never (1 point), sometimes (2 points), almost always (3 points), always (4 points)). In addition, the questionnaire includes an overall speech quality item, with four response categories (good, reasonable, poor, severe). All items refer to the last week.

A total SHI score was calculated by summing the first 30 items (score ranges from 0 to 120), with higher scores indicating higher levels of speech-related problems. No assumptions regarding missing data were made.

The SHI has been translated into Dutch and validated for use among head and neck cancer patients [36] and laryngeal cancer patients [35].

NQ_x121 Xerostomia - Groningen Radiation Induced Xerostomia (GRIX) (patients only)

Xerostomia is measured using the 14-item Groningen Radiation Induced Xerostomia (GRIX) [37]. The GRIX consists of four different subscales namely xerostomia during the day, xerostomia during the night, sticky saliva during the day and sticky saliva during the night. In addition a xerostomia total score and sticky saliva total score can be calculated.

Scores of all subscales were linearly transformed to a 0-100 scale in which a higher score indicates more xerostomia. Scores of both total scales were linearly transformed to a 0-200 scale, in which a higher score indicates more xerostomia. No assumptions were made regarding missing data.

The GRIX has been shown to be a valid measurement instrument for use among Dutch head and neck cancer patients treated with radiotherapy [37].

NQ_x122 Shoulder problems - Shoulder Disability Questionnaire (SDQ) (patients only)

The Shoulder Disability Questionnaire (SDQ) is a validated pain related disability outcome measure including 16 items describing common conditions that may induce symptoms in patients with disorders of the shoulder [38]. All items refer to the preceding 24 hours. Options are “yes”, “no” and “not applicable”. The “not applicable” category should be used when the condition referred to has not occurred during the preceding 24 hours.

A final score was calculated by dividing the number of “yes” scored items by the total number of items applicable and multiplying this score by 100. The final score ranges from 0 (no disability) to 100 (all applicable items scored “yes”), in which a higher score indicates greater impairment. A total score could be calculated when at least 12 items were completed.

The SDQ is a reliable and valid measurement instrument for use in Dutch patients after neck dissection [39].

NQ_x123 Fear of recurrence - Cancer Worry Scale (CWS) (patients only)

Fear of recurrence was evaluated with the 8-item cancer worry scale (CWS) [40, 41]. All items can be answered on a 4-point Likert scale ranging from almost never or not at all (1 point) to almost always or very much (4 points). All items refer to the last month.

A total summary score was calculated by summing the individual items, resulting in a score from 8 to 32. A higher score indicates a higher level of fear of recurrence. No assumptions were made regarding missing data.

A previous study among Dutch breast cancer patients showed that the CWS is a reliable and valid patient-reported outcome measure [42].

NQ_x124 Health care use – iMTA Medical Consumption Questionnaire (adjusted version)

Healthcare usage and received informal care was measured using the medical consumption questionnaire (iMCQ) [43]. The iMCQ contains questions on visits to different care providers, received personal care by a visiting nurse or nurse assistant, received home care, received informal care, participation in support groups and used medication in the last 3 months (medication data is available is available in datafile NQ_x131). In addition to the iMCQ a study-specific healthcare utilization form will be completed on HNC-related visits to the medical specialist, HNC-related day treatment and hospitalization by extracting data from medical files (available Q1 2026, datafile NQ_x133).

NQ_x125 Productivity costs – iMTA Productivity Costs Questionnaire

Productivity losses in the last 3 months were measured using the productivity costs questionnaire (iPCQ) [44]. This instrument measures productivity losses from formal work due to absenteeism and presenteeism. Absenteeism was measured as the number of days absent from work. Presenteeism was measured as the number of days with less productivity at work (while being at work) multiplied by the perceived amount of lost quantity of work on a 11-point scale. In addition, this data file contains information on (current) profession and question on changes in the working situation due to cancer.

NQ_x126 Income – Income

This file is not yet available for data release.

NQ_x128 Social support - Social support Social Support List – Interactions (SSL-I12)

Social support was assessed with the 12-item Social Support List – Interactions (SSL-I12) [45]. The SSL-I12 contains questions on frequency of everyday support (4 items), support in problem situation (4 items) and esteem support (4 items). All items can be answered on a 4-point Likert scale: seldom or never (0 point), now and then (1 points), regularly (2 points) and very often (3 points). All items refer to a general situation.

A total sum score for each of the three domains ranging from 0 to 12 and a total sum score ranging from 0 to 36 was calculated. A higher score indicates better social support. No assumptions were made regarding missing data.

A previous study in a Dutch elderly population found that the SSL-I12 has satisfactory psychometric properties [46].

NQ_x129 Concerns about patient – Caregiver Reaction Assessment (CRA) (caregivers only)

This questionnaire was completed by caregivers only. The CRA is an instrument designed to assess both negative and positive reactions to caregiving. All questions used the term 'partner', however caregivers were instructed to read "patient" in case the patient was not their partner. The CRA consists of 24 items over five domains: disrupted schedule, financial problems, lack of family support, health problems, and the impact of care giving on the caregiver's self-esteem.

Per domain a total mean score was calculated ranging from 1 to 5 in case at least 80% of the items of a domain were completed. A higher score on the disrupted schedule, financial problems, lack of family support and health problems domain indicates more negative reactions, whereas a higher score on the domain on impact of care giving on the caregiver's self-esteem indicate more positive reactions.

A previous study among Dutch partners of colorectal cancer patients showed that the CRA is valid [47].

NQ_x130 Physical activity - Physical Activity Scale for the Elderly (PASE)

Physical activity was assessed with the 13-item Physical Activity Scale for the Elderly (PASE), on duration and frequency of leisure time (6 items), household (6 items) and work-related physical activities (1 item) [48, 49]. All items refer to the last week.

For each of the 13 items a physical activity score was calculated by multiplying the amount of time spent in the activity by its corresponding weight. Consequently, a PASE score for leisure,

household and work-related physical activities can be calculated by summing the physical activity scores within these domains. In addition, a total PASE score can be calculated by summing all scores. A higher score indicates more physical activity. A total score was also calculate in case domain scores were missing (e.g. on work).

A previous Dutch study found that the PASE is a reasonable valid instrument [48].

NQ_x131 Medication

The data is available, the data is, however, not yet cleaned/coded.

NQ_x133 Study-specific healthcare utilization form based on medical files (available Q1 2026)

This file is not yet available for data release.

F. Patient-reported outcome measures (questionnaire B)

These patient/caregiver-reported outcome measures were completed by the patient/caregiver as part of questionnaire booklet B before start of treatment and at 3 and 6 months, and 1, 2, 3, 4 and 5 years after the end of treatment.

NQ_x202 Participation - Daily life Impact on Participation and Autonomy (IPA) (not yet available)

Participation in daily life was assessed with the Impact on Participation and Autonomy (IPA) questionnaire. The IPA measures participation and autonomy on five domains: home (7 items), family role (7 items), autonomy outside of the home (5 items), social relations (7 items), and work and education (6 items). All these items can be answered on a 5-point Likert scale, ranging from very good (0 points) to bad (4 points). In addition, the IPA measures the perceived experience of problems in daily life participation regarding mobility, self-care, family role, financial situation, leisure, social relations, helping others, work, and education and training (1 item each). These items can be answered as no problem, some problem or a big problem [50].

For each of the 5 domains a total mean score was calculated. A higher score indicates more barriers in participation and autonomy. As described in the manual at least 75% of the items within a domain need to be completed to obtain a valid total mean score [51]. For some research questions, however, other methods for data imputation may be more appropriate. In that case, data on item level can be used, which does not contain imputed data.

Psychometric properties of the IPA have been assessed previously among Dutch patients with neuromuscular disease, spinal cord injury, stroke, rheumatoid arthritis, or fibromyalgia [50].

NQ_x203 Self-perceived neurocognitive function - Cognitive Failures Questionnaire (CFQ)

Self-perceived neurocognitive function was measured using the 25-item Cognitive Failures Questionnaire (CFQ) [52]. Patients are asked to answer 25 questions over the last 4 weeks on a 5-point Likert scale: very often (4 points), often (3 points), every now and then (2 points), seldom (1 point), never (0 points).

A total sum score was calculated ranging from 0 to 100 in which a higher score indicates more cognitive failures. A total score was calculated in case less than 25% of the items were missing.

Psychometric characteristics have previously reported to be excellent [53]. However, to our knowledge, psychometric characteristics have not yet been assessed in a Dutch (cancer) population.

NQ_x204 Self-efficacy - Generalized Self-Efficacy Scale (GSE)

Self-efficacy was assessed using the 10-item Generalised Self-Efficacy scale (GSE) [54, 55]. All items can be answered on a 4-point Likert scale: not at all true (1 point), hardly true (2 points), moderately true (3 points) and exactly true (4 points). All items refer to the current situation.

A total sum score was calculated ranging from 10 to 40 in which a higher score indicates better self-efficacy. In this dataset, a total score was calculated when less than 4 items were missing [56]. For some research questions, however, other methods for data imputation may be more appropriate. In that case, data on item level can be used.

NQ_x205 Sleep quality - Pittsburgh Sleep Quality Index (PSQI)

The Pittsburgh Sleep Quality Index (PSQI) was used to assess subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction [57]. All items refer to the last month.

On each of these seven scales a total score was calculated ranging from 0 (better) to 3 (worse), which can be summed into a total sum score ranging from 0 (better) to 21 (worse). No assumptions for missing data we made on the domains subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, use of sleep medication, and daytime dysfunction. On the domain on sleep disturbances a total score was calculated in case at least eight of the first nine questions were answered. In case the tenth question was missing (i.e. on other reasons), it was recoded into no. A total score was calculated in case at least 6 of the 7 scales contained a total score.

Psychometric properties of the PSQI have been investigated in cancer patients (in different languages) [58-64]. However, to our knowledge, psychometric properties of the PSQI have not yet been investigated in a Dutch (cancer) population.

NQ_x206 Life events - Brugha

Important stressful life events during their life and in the past year such as death or serious illness of other family members, unemployment and violence experience, were assessed with the 13-item Brugha questionnaire/List of Threatening Experiences [65]. At the follow-up measurements (i.e. 3, 6, 1, 2, 3, 4 and 5 years follow-up) only stressful life events within the past year were presented.

In previous literature several methods have been used to calculate an overall score on this patient-reported outcome measure [66-68]. To our knowledge no validation study has been performed among Dutch cancer patients, therefore, this dataset only contains single items.

NQ_x207 Post-traumatic stress - Impact of Event Scale-Revised (IES-R) (patients only)

The 22-item questionnaire Impact of Event Scale – Revised (IES-R) was used to assess post-traumatic stress disorder (PTSD). The revised version measures PTSD symptoms (intrusion, avoidance and hyper-arousal) and is often used in medically ill patients. All items refer to the last week. Also an additional question on future negative events is added.

In previous literature different factor structures of the IES-R have been reported [69]. In this dataset scores for the 5-factor structure are provided: intrusion (6 items), sleep disturbance (3 items), hyperarousal (5 items), avoidance (6 items), numbing (2 items). No assumptions were made regarding missing data.

The IES-R is used as a valid and reliable measurement for PTSD [70, 71].

NQ_x208 Loneliness - Loneliness Scale (de Jong Gierveld)

The 11-item De Jong Gierveld Loneliness Scale was used to measure emotional (6 items) and social loneliness (5 items) [72, 73]. Each of the items can be answered on a 3-point scale: yes, more or less, or no.

A total emotional loneliness score was calculated by summing the number of items on which a person answered 'yes' or 'more or less'. This results in a score ranging from 0 to 6, a higher score indicates higher emotional loneliness. A total social loneliness score was calculated by summing the number of items on which a person answered 'more or less' or 'no'. This results in a score ranging from 0 to 5, a higher score indicates higher social loneliness. Finally, a total loneliness score was calculated by summing the scores of the two scales. The emotional loneliness and sol loneliness scores are only valid in case there is no missing data. For the total loneliness score one item may be missing. Based on the total loneliness score participants can be divided into four groups: not lonely (score 0 to 2), moderate (score 3 to 8), severe (score 9 or 10) very severe (score 11) [74].

NQ_x209 Hearing - Caron

Hearing was assessed via the 15-item Caron questionnaire on hearing. The first question measures the participants' opinion on their hearing on the following scale: good (0 points), slight hearing problems (2 points), moderate hearing problems (3 points) and serious hearing problems (4 points).

Based on the first 15 items a total sum score was calculated ranging from 0 to 60. A score of 14 is often used as cut-off for a consultation with a care provider [75]. A total score was calculated in case at least 14 of the 15 items were completed.

To our knowledge the Caron has not yet been validated among Dutch (cancer) patients.

NQ_x210 Sexual functioning (men) - International Index of Erectile Function (IIEF)

The 15-item International Index of Erectile Function (IIEF) was used to assess male sexual functioning across five domains, including erectile function (6 items), orgasmic function (2 items), sexual desire (2 items), intercourse satisfaction (3 items), and overall satisfaction (2 items) [76, 77]. All items refer to the past four weeks.

On each of the domains a total sum score was calculated. A higher score indicates better functioning, while a domain score of zero indicates no sexual activity during the past month. No assumptions were made regarding missing data.

The IIEF has previously been validated, including linguistic validation in the Dutch language [76].

NQ_x211 Sexual functioning (women) - Female Sexual Function Index (FSFI)

Sexual function in women was evaluated by means of the 19-item Female Sexual Function Index (FSFI) across six domains: desire (2 items), arousal (4 items), lubrication (4 items), orgasm (3 items), satisfaction (3 items), and pain (3 items) [78]. All items refer to the last four weeks.

For each of the domains a total score was calculated by summing scores of all items and multiplying this by its corresponding weight. In addition an overall total score can be calculated by summing total scores of all domains. A higher score indicates better functioning, while a score of zero indicates no sexual activity during the past month. No assumptions were made regarding missing data.

Psychometric properties of the FSFI have previously been investigated in Dutch women with and without sexual complaints [79].

NQ_x212 Supportive care needs - Supportive Care Needs Survey Short-Form34 (SCNS-SF34) and SCNS head and neck cancer module (SCNS-HNC) (patient only)

Supportive care needs were measured using the 34-item Short-Form Supportive Care Needs Survey (SCNS-SF34) [80-82] and the head and neck cancer-specific module (SCNS-HNC) [82]. The SCNS-SF34 consists of 34 items which were originally reported to have five underlying constructs, namely physical & daily living, psychological, sexuality, patient care & support and health system & information needs [80, 81]. In a previous study among Dutch head and neck cancer patients, four underlying constructs using 33 items were found: physical & daily living needs (5 items), psychological needs (10 items), sexuality needs (3 items) and health system, information & patient support needs (15 items) [82]. The SCNS-HNC contains 11 items on two underlying constructs, namely HNC-specific functioning needs (8 items) and lifestyle needs (2 items), and one single item on care of your stoma and/or voice prosthesis.

The SCNS-SF34 and the SCNS-HNC measure the need for supportive care from the patient's perspective in the last month on a 5-point, two-level response scale [81]. The first level consists of two

broad categories of need, i.e. 'no need' and 'some need'. The 'no need' scale is further subdivided into '1=not applicable' for issues that were no problem to the patient and '2=satisfied' for issues on which a patient needed support but the support was satisfactory. The 'some need' level has three categories indicating the level of need for additional care: 3=low, 4=moderate and 5=high. A total score per domain can be calculated and converted to a 0-100 score, with a higher score indicating a higher level of SC needs. In the dataset scores for 4 factor structure are provided. Missing data on the SCNS-SF34 and SCNS-HNC was imputed by the mean score of the other items of the particular domain in case less than half of the items within the domain were missing [81].

The SCNS-SF34 and SCNS-HNC have good validity and reliability among head and neck cancer patients [82].

Remark: At 3,6 and 12 months follow-up, patients did not complete the SCNS-HNC.

NQ_x213n Supportive care needs - Supportive Care Needs Survey Partners and Caregivers (SCNS-P&C)

Supportive care needs were measured using the 45-item Supportive Care Needs Survey for Partners and caregivers (SCNS-P&C). The SCNS-P&C consists of 45 items which were reported to have four underlying constructs, namely emotional and relational needs, health care and illness related needs, practical needs and work and social needs.

The SCNS-P&C measures the need for supportive care from the caregiver's perspective in the last month on a 5-point, two-level response scale. The first level consists of two broad categories of need, i.e. 'no need' and 'some need'. The 'no need' scale is further subdivided into '1=not applicable' for issues that were no problem to the caregiver and '2=satisfied' for issues on which a caregiver needed support but the support was satisfactory. The 'some need' level has three categories indicating the level of need for additional care: 3=low, 4=moderate and 5=high. A total score per domain can be calculated and converted to a 0-100 score, with a higher score indicating a higher level of needs. Missing data on the SCNS-P&C was imputed by the mean score of the other items of the particular domain in case less than half of the items within the domain were missing.

The SCNS-P&C has good validity among partners of breast cancer patients [83].

NQ_x214 Leisure activities

Details about leisure time were assessed through a 15-item study specific questionnaire. This questionnaire includes questions on participation in several activities like visiting a cultural institution, going to a restaurant or participating in sport activities. In addition, it contains questions on usage of computers, reading the newspaper and frequency of social contact with family and friends.

G. Field work assessments (patients only)

The following measures were completed by the patient as part of the fieldwork assessments before start of treatment, and at 6 months, 1, 2 and 5 years after the end of treatment.

NQ_x325 Report Case Form (RCF) (available Q4 2025)

This datafile contains coded information from the RCF form completed by the fieldworker at every fieldwork assessment.

NQ_x302 Anxiety – WHO - Composite International Diagnostic Interview

The WHO-Composite International Diagnostic Interview version 2.1 (CIDI) was used to diagnose depression and anxiety disorders according to the DSM-IV criteria. The life-time CIDI allows for the determination of the history, recency, duration and age of onset of episodes of anxiety or depression [84-88]. The following disorders were interrogated: major depressive disorder (MDD), generalized anxiety disorder (GAD), social phobia (SOC), panic disorder (PAN) and agoraphobia (AG). This particular dataset provides information on anxiety disorders GAD, SOC, PAN, and AG.

Remark: The CIDI was not completed at 6 months follow-up.

NQ_x303 Depression – WHO - Composite International Diagnostic Interview

The WHO-Composite International Diagnostic Interview version 2.1 (CIDI) was used to diagnose depression and anxiety disorders according to the DSM-IV criteria. The life-time CIDI allows for the determination of the history, recency, duration and age of onset of episodes of anxiety or depression [84-88]. The following disorders were interrogated: major depressive disorder (MDD), generalized anxiety disorder (GAD), social phobia (SOC), panic disorder (PAN) and agoraphobia (AG). This particular dataset provides information on major depressive disorder MDD.

Remark: The CIDI was not completed at 6 months follow-up.

NQ_x304 Verbal learning and verbal recall: immediate recall – Hopkins Verbal Learning Test (HVLT)

The Hopkins Verbal Learning Test Memory was used to measure verbal learning and verbal recall (immediate recall, delayed recall and delayed recognition) [89]. In this test 12 words are read out loud by the research assistant. Immediately after reading the words out loud, the participant is asked to recall as may words as possible (trial 1). This is repeated twice with the same list of words (trial 2 and 3). After 20-30 minutes participants are asked to recall the words (trial 4), see dataset NQ_x310 Hopkins Verbal Learning Test (HVLT) - Delayed Recall. In addition, the recognition of words after 20-30

minutes is measured. The research assistant reads out loud a list of words, after each word the subject is asked whether the word was on the list or not.

For each home visit a different list of words was used.

NQ_x305 Visual motor scanning speed – Trailmaking A

Visual motor scanning speed was measured using Trailmaking A [90]. In this task subjects are asked to link dots on paper in a numbered order (1,2,3,..), as fast as possible. Participants have 3 minutes to complete this task (at most). This dataset contains information on time to complete the task, or in case participants were not able to complete the task within time, the progress after 3 minutes. Also, qualitative remarks of the research assistant on the participant's understanding of the task, independency in correcting errors, or other remarks are provided in this dataset.

NQ_x306 Executive functioning – Trailmaking B

Executive functioning was measured using Trailmaking B [90]. In this task participants are asked to link dots on paper ordered by number and letter (1,A,2,B,3,…) as fast as possible. Participants have 5 minutes to complete this task (at most). This dataset contains information on time to complete the task, or in case participants were not able to complete the task within time, the progress after 5 minutes. Also, qualitative remarks of the research assistant on the participant's understanding of the task, independency in correcting errors, or other remarks are provided in this dataset.

NQ_x307 Verbal fluency – Controlled Oral Word Association Test (COWA)

Verbal fluency was measured using the controlled oral word association test [91]. Participants are asked to report as many words as possible beginning with a specified letter within one minute. This task is performed three times with different letters. The dataset provides the number of words reported by the participant.

For the home visit at baseline and 12 months follow-up and 6 months follow-up and 24 months follow-up, the same sets of letters were used (respectively BDH and PMC). At 6 months follow-up, by mistake, some patients received the wrong set of letters (i.e. BDH instead of PMC).

NQ_x308 Daily life - Instrumental Activities Daily Life (IADL)

Instrumental activities of daily life was measured using the Instrumental Activities of Daily Life (IADL) measure [92]. This instrument measures whether patients can independently perform 8 instrumental activities of daily life, including using the telephone, shopping, preparing a meal, household tasks, doing the laundries, transportation, responsibility for own medication and performing financial administrative tasks.

A total IADL score can be calculated ranging from 0 to 8 in which a higher score indicates less dependence. No assumptions were made regarding missing data.

NQ_x309 Pain – Brief Pain Inventory (BPI)

The Brief Pain Inventory (BPI) was used to assess types of pain, pain history, intensity, location, quality, and the degree of pain interference with activities of daily life [93, 94]. Follow-up questions were only assessed if patients had pain. If patients did not experienced pain after using pain medication, follow-up questions were also not assessed.

A mean score for pain severity can be calculated, based on the three questions on pain severity, ranging from 0 (no pain) to 10 (pain as bad as you can imagine). In addition, a mean score for pain interference with activities of daily living can be calculated, based on the 7 items on pain interference, ranging from 0 (no interference) to 10 (completely interferes). Mean scores were only calculated for patients with pain. Some assumptions were made regarding missing data.

The BPI has previously been used among Dutch cancer populations [95-97]. To our knowledge, however, the Dutch version has not yet been validated.

NQ_x310 Verbal learning and verbal recall: Delayed – Hopkins Verbal Learning Test (HVLT) – delayed recall

The Hopkins Verbal Learning Test Memory was assessed to measure verbal learning and verbal recall (immediate recall, delayed recall and delayed recognition) [89]. In this test 12 words are read to the participants by the research assistant. Immediately after reading the words out loud, the participant is asked to recall as may words as possible (trial 1). This is repeated twice with the same list of words (trial 2 and 3), see dataset NQ_x304. After 20-30 minutes participants are asked which words they still remembered (trial 4). In addition, the recognition of words after 20-30 minutes is measured. The fieldworker reads out loud a list of words, after each word the participant is asked whether the word was on the list or not. For each home visit a different list of words was used.

NQ_x311 Blood pressure – Systolic and diastolic blood pressure, and fever and cold

Systolic and diastolic blood pressure (mmHg) and pulse (bpm) were measured twice while patients were seated, using an electronic Omron sphygmomanometer (Omron M6). In addition, this dataset includes information on having had a fever or cold in the past week and at the time of the measurement.

NQ_x312 Body composition - Weight, height, BMI, circumferences (waist and hip), skinfolds

Measurements of height, weight, circumferences (hip and waist), and skinfolds were used to estimate body composition. Height (in cm) was self-reported by the patient or collected from the hospital information system. Weight (in kg) was measured using a seca scale. Patients were weighted without shoes. Based on height and weight the subject's BMI was calculated (m/kg^2). Hip circumference and waist circumference (in cm) were measured with the subject in standing position. Skinfolds (biceps, triceps, subscapular and supra-iliacal) were measured using the Harpenden Skinfold Caliper HSK-BI (in mm) at the non-dominant side. All skinfold measurements were performed twice.

NQ_x313 Pulmonary function – Peak flow

Pulmonary function was measured by the peak expiratory flow (l/min). This is a subject's maximum speed of expiration measured by peak flow monitoring. The peak flow monitor (MicroPeak) measures the airflow through the bronchi and thus the degree of obstruction in the airways. The test was performed three times.

Remark: Due to COVID-19 peak flow was not measured 5 years after the end of treatment.

NQ_x314 Muscle strength – JAMAR handgrip dynamometer and 30s chair stand test

Upper extremity muscle strength (in kg) was assessed using a JAMAR® grip strength dynamometer according to standardized measurement protocol [98-100]. Maximal handgrip strength was performed two times for each hand.

Lower extremity muscle strength was tested by the 30s chair stand test. The 30s chair stand test is valid and reliable measure of lower limb strength in older adults [101]. The subject was asked to stand upright from a chair with their arms folded across the chest, then to sit down again and then repeat the action at his/her own/fastest pace over a 30 seconds period. The final test score is the number of times that the subject rises to a full stand from the seated position with arms folded within 30 seconds [102-104].

NQ_x315 Nutritional status – Mini Nutritional Assessment (MNA)

To determine nutritional status the 18-item Mini Nutritional Assessment was used [105, 106]. Based on the first 6 items a screening score ranging from 0 to 14 was calculated. A score from 0 to 7 indicates malnourishment, a score between 8 and 11 indicates risk at malnourishment and a score between 12 and 14 indicates normal nutritional status. In case a patient scored <=11, 12 follow-up questions were asked. Based on the other 12 items an assessment score was calculated, ranging from 0 to 16. Also, a total score, which is the sum of the screening score and the assessment score, was calculated, ranging from 0 to 30. A total score lower than 17 indicates malnourishment, a score between 17 – 23.5

indicates risk of malnourishment, and a score higher than 23.5 indicates normal nutritional status. No assumptions were made regarding missing data.

NQ_x317 Oral and shoulder function – Functional Rehabilitation Outcome Grades (FROG)

Oral and shoulder function were assessed using the Functional Outcome Rehabilitation Grade test (FROG) [107]. All 48 items of the FROG are scored by a trained nurse on a structured form. The FROG comprises 7 scales: shoulder (3 tests, score range 0–6), mandible (5 tests, score range 0–9), teeth (2 tests, score range 0–6), lips (6 tests/10 items, score range 0–14), tongue (9 tests/12 items, score range 0–28), oropharynx (5 tests/8 items, score range 0–12), and saliva/xerostomia (2 tests, score range 0–5). In addition, the FROG contains 6 single items on prosthesis upper jaw, prosthesis lower jaw, number of own front teeth, presence of edentate, whether the subject eats with prosthesis upper jaw or lower jaw. In patients who fully depend on their PEG tube, tongue function cannot be scored because testing this subscale of the FROG requires oral intake.

Scores were summarized to a total scale, with a score ranging from 0 to 80. On all FROG scales, a higher score indicates a better level of function. No assumptions were made regarding missing data.

NQ_x318 Cardiorespiratory fitness – Chester Step test

To determine cardiorespiratory fitness, the Chester step test was performed. The step height varies for different participants based on the respondent's age and history of physical activity behavior. The initial step rate is 15 steps per minute and every 2 minutes the step rate increases by 5 steps per minute. The test ends when the subject reaches 80% of age predicted maximum heart rate and/or a rating of perceived exertion (RPE) of 14 on Borg's 6–20 scale [108-110]. During the test, heart rate was measured using a sport-tester (Polar RS 800CX or Polar V800). For patients using beta blockers, the age predicted maximum heart rate was adjusted (i.e. 220 minus age minus 30).

The VO2max was estimated by AmsterdamUMC (project Dr. F Jansen) by plotting all valid heart rates on a graphical data sheet and, using Excel, plotting a line of best fit between the measured heart rates. A perpendicular line was drawn from the point where the line of best fit crosses the maximum heart rate, indicating the VO2max estimate on the X-axis. A minimum of 2 valid heart rates was needed to estimate VO2max.

NQ_x319 Mouth

This data file contains questions related to the oral rinse, including date of oral rinse sample, date and time of last teeth brushing, data and time of last meal or drink, time of last cigarette, frequency of brushing teeth, whether the patient has a denture (upper jaw and lower jaw), and how often the

patient uses his or her denture. Also information on cavities, bleeding gums, red or swollen gums and blisters or ulcerations in the mouth, toothache when drinking warm or cold drinks, or when chewing, lost/loose/broken teeth, bad breath, and dry mouth in the last year is collected. Furthermore, this data file contains information on usage of antibiotic in the last 3 months (including date and name), number of teeth, periodontitis, general health of teeth and gums, ever being treated for a gums disease, or ever having had loose teeth.

NQ_x322 Toxicity - Common Terminology Criteria for Adverse Events (CTCAE)

Clinician-rated toxicities were measured by a physician using the CTCAE (version 5.0) at 5 years follow-up only. The following toxicities were assed: pharyngeal fistula, oral cavity fistula, dysphagia, aspiration, dry mouth, soft tissue fibrosis, peripheral motor neuropathy, peripheral sensor neuropathy, brachial plexopathy, cranial neuropathies, myelitis, injury to the carotid artery, trismus, osteonecrosis of the jaw, pharyngolaryngeal pain, oral pain, neck pain, face edema, neck edema, voice alteration, tinnitus, hearing impaired and hypothyroidism. All toxicities were graded as 0 (toxicity is not present) or a score ranging from 1 to 3 (or 4 or 5). A higher score indicated a higher level of toxicity and an increased need for intervention. Toxicities were scores as "na: not assessed" in case assessment of that specific type toxicity was not possible (e.g. due to physical limitations).

NQ_001 Dietary intake – Recall dietary intake

To be able to assess changes in dietary intake during and after treatment, each patient completed a 24 hour recall interview at a randomly chosen day, representative for their regular intake [111]. This recall takes approximately 20-30 minutes and was assessed at time of home visit or after the home visit via telephone. At first, a quick list is completed, which provides a short overview of dietary intake in the previous 24 hours. Intake is coded per meal (before breakfast, breakfast, during the morning, lunch, during the afternoon, diner, during the evening). After completing the quick list, more detailed information is gathered, including for example information on type of bread and size of servings.

Data on dietary intake will need to be cleaned by the researchers themselves. Following the study procedures, the cleaned data need to be brought into the NET-QUBIC Data Warehouse for use in future studies without charges. Currently, researchers from the Hanze University of Applied Science (project leader Prof Jager-Wittenaar) are using/cleaning the dietary intake data.

NQ_002 Objectively measured physical activity - Accelerometer

Objective levels of physical activity was assessed using an accelerometer (ActiTrainer, Manufacturing Technology Inc., Pensacola, FL), a lightweight physical activity monitor. Patients were instructed to wear the accelerometer at least 7 days, including one weekend day, on their right hip, from the

moment they wake up until they go to sleep [112, 113]. A valid wear day was defined as a day with at least 10 hours of recorded data, excluding periods of ≥60 consecutive minutes without movement (zero counts), which were considered non-wear time. To be included in the analysis, participants needed at least five valid days. Data was processed for project 1918 (by Dr. Speksnijder/Drs Zuijlen) using ActiLife6 software (ActiLife, Pensacola, FL, USA). Physical activity (PA) intensity was expressed in counts per minute (cpm) and classified using Freedson cut-points: sedentary (<100 cpm), light-intensity (100–1,951 cpm), and moderate-to-vigorous physical activity (MVPA) (≥1,952 cpm). PA was analyzed using vertical axis counts (CPM_Axis1 in SPSS), with the average cpm over the entire wear time representing general activity levels during each period. MVPA was assessed by calculating the average daily minutes spent at ≥1,952 cpm (MVPA_PD in SPSS), providing insight into patients' capacity for engaging in moderate to vigorous activities.

NQ_003 Heart rate – Polar

During the Chester Step Test, participant's heart rate (bpm) was measured using a sport-tester (Polar RS 800CX or Polar V800). Information on the heart rate during each phase of the Chester Step Test (i.e. each step rate) is already part of datafile NQ_x318. This datafile provides more thorough information, if needed.

This heart data will also need to be cleaned by the researchers themselves. Following the study procedures, the cleaned data need to be brought into the NET-QUBIC Data Warehouse for use in future studies without charges.

NQ_004 Audio files

The interviews/home visits were completely audio-recorded for quality purposes. Also, a voice test was performed in order to objectively evaluate a patient's voice. During this voice test patients were asked to read out loud 10 sentences of a text (i.e. vijvervrouw) and to read out loud of 50 words. In case a mistake was made patients were asked to read the entire sentence or word again. The audio files of the interview will not be released and are only for quality purposes.

NQ_005 DICOM-RT data

"The treatment parameters for patients treated with radiotherapy include, among other things, the CT data, the delineated target areas and organs at risk, and the dose distribution. Prof. Langendijk en Dr. Raaijmakers are currently working on this side project.

H. Biobank data

In patients, blood, saliva samples and oral rinses were obtained at every visit (baseline, 6 months, a, 2 and 5 years) allowing biomarker analyses. Tumour biopsies were collected at baseline. In caregivers, blood and oral rinses were obtained at baseline only.

Tumour tissue

Tumour tissue was obtained during panendoscopy according to the local Standard Operating Procedures, and frozen in liquid nitrogen and stored in liquid nitrogen.

Oral rinse

Oral rinses were taken during the home visits. Subjects gargled with 10 ml of water. After receipt, the oral rinses were aliquoted in 2 ml vials and stored at -80°C.

Blood

Biomarkers associated with cardiovascular disease, metabolic syndrome and physical functioning were assessed in blood with routine assays, and these data are available. The remaining blood was processed and stored in the NET-QUBIC biobank at -80°C. Serum, plasma, platelets, (also cryopreserved peripheral blood mononuclear cells (PBMC) and pellets of polymorphic nuclear cells (PMN)), and blood cell DNA and RNA were isolated and stored.

Saliva

Four saliva samples were collected by the enrolled subjects themselves: at the time of awakening (T1), 30 minutes post-awakening (T2), 60 minutes post-awakening (T3), and at 22:00 h (T4) [114]. The subjects were instructed to send the samples by mail to the research centre. The salivates were stored at the same vial labelled with date and time.

NQ_x500 Available biobank samples

This datafile contains information on all collected biobank samples (samples were verified) at baseline and at 6 months, 1, 2 and 5 years follow-up. Samples which are already used are also part of this datafile.

NQ_x501 Blood: Routine assays (patients only)

This datafile contains information on all routine assays determined in blood, namely Hemoglobin, Hematocrit, Platelet, Leucocyte and differential counts, Total cholesterol, High-density lipoprotein

(HDL)-cholesterol, Low-density lipoprotein (LDL)-cholesterol (calculated), Triglyceride, C-reactive protein (CRP), Calcium, Albumin, Lactate dehydrogenase, Creatinine, Thyroid stimulating hormone (TSH), Free T4, and Estimated glomerular filtration rate (eGFR). Routine assays from baseline to 2 years after treatment were performed in four different labs, namely in Amsterdam (VUmc), Groningen, Utrecht and Nijmegen. Routine assessments at 5 years follow-up were all performed in Amsterdam (VUmc).

NQ_x502 Serum: cytokines

This datafile contains information on the values of cytokines, which was assessed as part of the work package on depression of prof. Verdonck-de Leeuw (project 1914) and the YIG-project of Dr. Jansen. Cytokines investigated were Interleukin-10 (IL-10), Interleukin-6 (IL-6) and Tumor necrosis factor-alpha (TNF-α). These cytokines were evaluated in samples of serum (500 µl) using an ELISA based technology that uses electrochemiluminescence for detection on a Meso Scale Discovery Quickplex SQ 120 Imager (cat. # K15049-Series, K15052-Series, K15053-Series, K0015056-Series, Meso Scale Discovery, Rockville MD). Samples were analyzed in three batches, namely batch 1 (2019: baseline and M6 samples of patients), batch 2 (2020: M12 and M24 samples patients and T0 samples informal caregivers) and batch 3 (M60 samples of patients). Batch 1 had an intra-assay CV: 4,7% (IL-6), 4,0% (IL-10) and 3,7% (TNFα) and an inter-assay CV: 7,9% (IL-6), 5,5% (IL-10), and 8,0% (TNFα). Batch 2 had an intra-assay CV: 6.5% (IL-6), 5.8% (IL-10) and 3.1% (TNF-alpha). Batch 3 had an intra-assay CV: 11.2% (IL-6), 5.8% (IL-10) and 4.2% (TNF-alpha).

NQ_x503 Saliva: Cortisol (patients only)

This datafile contains information on the cortisol levels which was assessed as part of the work package on depression of prof. Verdonck-de Leeuw (project 1914) and the YIG project of Dr. Jansen. Saliva samples were taken at: the time of awakening (T1), 30 minutes post-awakening (T2), 60 minutes post-awakening (T3), and at 22:00 h (T4) in saliva. Patients were instructed to send the saliva samples by mail to the main research centre (Amsterdam, location VUmc). The salivates were stored at the same vial labelled with date and time. Salivary cortisol concentrations were measured in the Endocrine Laboratory of the Amsterdam UMC (AMC) with the use of an isotope dilution LC–MS/MS method. In short, internal standard (13C3-labeled cortisol, Isosciences) was added to the samples. Samples were extracted by supported liquid extraction (Biotage) and analysed on a LC-MS/MS (Xevo TQ-S Micro LC-MS-MS System, Waters Corporation). Samples were analyzed in two batches, namely batch 1 (2019: baseline and M6 samples of patients) and batch 2 (2020: M12 and M24 samples of patients). The lower limit of quantitation was 1.0 nmol/L in batch 1 and 0.3 nmol/l in batch 2. The intra-assay variation was 5% and 3% at cortisol concentrations of 2 and 15 nmol/L. The inter-assay variation of batch 1 was < 9%

over the whole concentration range. The inter-assay variation of batch 2 was 15% at a level of 0.5 nmol/L, 6% at a level of 2 nmol/L and <5% at higher cortisol concentrations.

NQ_x504 Serum: testosterone and SHBG (patients only)

This datafile contains information on the sex hormones: testosterone and Sex Hormone Binding Globuline (SHBG), which was assessed as part of the project on sexuality of prof. I.M. Verdonck-de Leeuw (project 1909). Testosteron and SHBG were assessed in two batches. In batch 1 (pilot study) sex hormones were determined in 40 patients at baseline and 6 months follow-up in serum samples of 750 µl. In batch 2 (female population) baseline and follow-up samples of the female patients were analyzed. Total testosterone level (bound and unbound) was measured using Liquid Chromatography with tandem mass spectrometry (LCMSMS). The inter-assay variation is usually 5% and 8% at testosterone concentrations of 16 and 1 nmol/L. SHBG was evaluated using an automized non-competitive (sandwich) immunoassay (Abbott, Architect i2000). The inter-assay variation is 5%. These values were determined in Amsterdam (AMC).

NQ_x505 EDTA clinical genetics: telomere length

This datafile contains information on telomere length at baseline. Telomere length was assessed as part of the main project of NET-QUBIC. Telomere length was determined at baseline using the EDTA samples of the clinical genetics department. Telomere length was determined by UCSF in San Francisco (Jue Lin/Elizabeth Blackburn Lab). Samples were provided by AmsterdamUMC (20ul at 30ng/u in 96 well plates (Biorad plates (Cat# HSP9601)) and were measured in duplo. Telomere length will be assessed using qPCR.

I. Caregiver-reported outcome measures after the patient died (one-time)

In case the patient died, caregivers were asked to complete the Inventory of Traumatic Grief which measures maladaptive symptoms of grief. In addition, caregivers were asked to complete the questionnaire on smoking, alcohol consumption, drug use, the EQ-5D, EORTC QLQ-C30, HADS, MFI, iPCQ, iMCQ, SSL-I12, PASE, IPA, CFQ, GSE, PSQI, CARON and the leisure activity questionnaire one last time.

NQ_x215 Inventory of traumatic grief

The Inventory of Traumatic Grief measures maladaptive symptoms of grief. This questionnaire has been shown to be reliable and valid among Dutch adults who suffered the loss of a first-degree relative [115]. As, so far, only few caregivers completed the inventory of traumatic grief, this data file will not yet be released.

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