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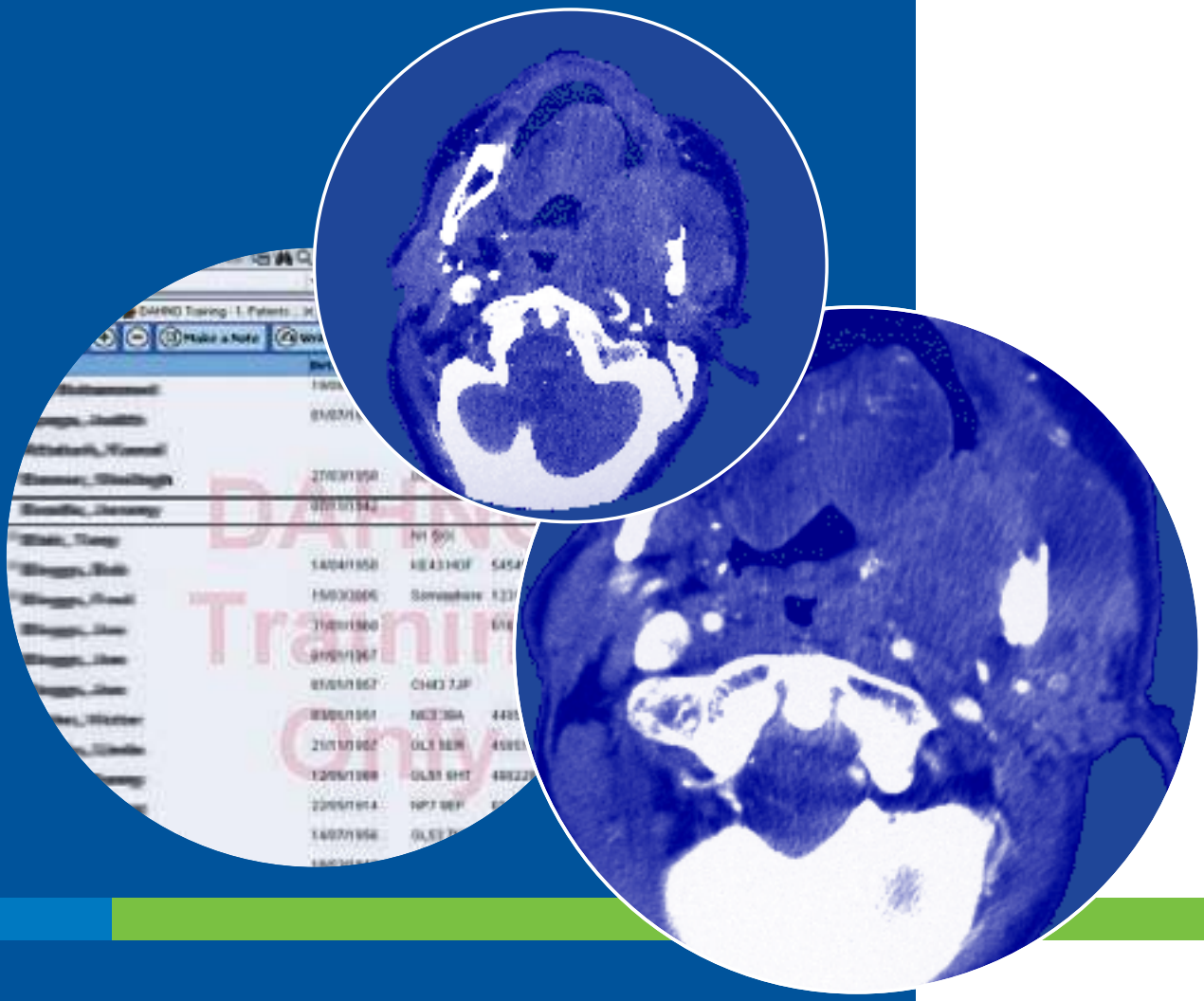
DAHNO first annual report: Key findings from the National Head and Neck Cancer Audit



Report for the Audit Period
January 2004 to November 2005

Healthcare Commission

BAHNO
British Association of Head and Neck Oncologists

"This first report from the DAHNO Project provides a fascinating insight into the current delivery of head and neck cancer services in the UK. The data presented will help to inform healthcare providers and acts as a baseline for monitoring changes in service required to meet recent Improving Outcomes Guidance."

Dr Chris Nutting BSc MRCP FRCR MD, Consultant and Hon. Senior Lecturer in Clinical Oncology,
Lead for Head and Neck Unit, Royal Marsden Hospital

"Cancer networks should encourage participation in projects such as DAHNO, which can help inform decisions around the provision of services and improvement of patient care."

Claire Barralet, Cancer Data Manager, Arrowe Park Hospital,
on behalf of the Merseyside and Cheshire Cancer Network

"The audit is in its infancy collecting data on head and neck cancers; it has been a long awaited store of information. The Let's Face It charity hopes the DAHNO audit will expand its precision by reporting on techniques on reconstruction e.g. plastic surgery or prosthetic reconstruction and patient rehabilitation."

Christine Piff - Founder and Chief Executive of Let's Face It

"The DAHNO audit is the first attempt to build a comprehensive, UK-wide picture of head and neck cancer care in the UK. By the very nature of its size and scope, this first report should be regarded as both a snapshot of how UK head and neck cancer services are presently shaping up and, importantly, as a feasibility study for large-scale national electronic data collection in a complex field of oncology. Of course, there are gaps and question marks in many places, but as far as these twin goals go, it has been a remarkable success. Thirty-four networks contributed data which was over 80% complete in many key areas. The validity of the data is demonstrated by the way the patterns reflect large published series, other audits or simply common sense and consensus opinion, both nationally and internationally. However, some of the questions it raises are tantalising, such as the patterns of use of chemotherapy, apparent lack of involvement of paramedical staff or trends in choice of operation.

DAHNO has succeeded in showing national data collection is feasible, and has given us an outline of the way we presently deliver care. The data quality will improve, and with it the value of the output. Having embarked on this course, we owe it to head and neck cancer patients, in many ways the most deprived and ignored group in oncology, to continue to improve our data collection. Only in this way can we really target the important gaps in provision, locally or nationally, press for resources and reorganisation to cope, and direct research to the real problem areas."

Martin Birchall, University of Bristol, ENT Surgeon

"*The head and neck community leads the way in publishing the first ever national site-specific cancer audit. As the DAHNO project evolves over the years it will be pivotal in helping clinicians across the country provide quality, patient-focused care with an evidence base."*

Mr Cyrus Kerawala FDSRCS, FRCS, Consultant Oral and Maxillofacial Surgeon, Royal Surrey County Hospital,
Guildford, Lead Clinician for Head and Neck Cancer - Surrey, West Sussex and Hampshire Tumour Network

NHS
Health and Social Care
Information Centre

DAHNO first annual report:
Key findings from the National Head and Neck Cancer Audit

Full report for the audit period January 2004 - November 2005
Version 1.0

Healthcare Commission

BAHNO
British Association of Head and Neck Oncologists

Report for the national head and neck cancer audit for period January 2004 to November 2005

This first report for the national head and neck cancer audit, which began in January 2004, presents data collected on new registrations to September 2005 and treatment data to November 2005. The report reflects findings from the analysis, and provides recommendations for improving data quality and completeness.

The DAHNO Project aims to improve data submission levels, and from this, provide comparative feedback to NHS trusts, with the ultimate aim of improving patient care.

Electronic copies of this report can be found at **www.dahno.com** Alternatively, further printed copies can be ordered by contacting the DAHNO Helpdesk on **01392 251 289**, or by emailing **helpdesk@dahno.com.** A brief summary report will compliment this report following its publication.

For further information about this report, email **NCASPinfo@ic.nhs.uk** or contact:

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Acknowledgements

The national head and neck cancer audit was commissioned and sponsored by the Healthcare Commission and developed in partnership with the British Association of Head and Neck Oncologists (BAHNO).

Throughout the development and rollout, a number of key individuals have provided considerable contribution. These include the DAHNO Project Team; Chair Richard Wight, Vice Chair Graham Putnam, Project Manager Annamarie O'Connor, Senior Project Manager Steve Dean (Cancer Audits), CCAD Project Manager David Cunningham, DAHNO Developer Ronnie Brar, Project Support Officer Natasha Hinds-Payne; and previous Project Manager Beverley Meeson.

The following groups have supported the audit, including; the Data Management and Analysis Group; the User Group; the Head and Neck Clinical Reference Group, (membership lists in appendix 8) and colleagues from the Royal College of Surgeons Clinical Effectiveness Unit.

We would like to acknowledge the Expert Panels (larynx and oral cavity) who contributed greatly to the annual report; Patrick Bradley, Martin Birchall, Mark Watson, David Howard, Jon Hayter, Cyrus Kerawala, Simon Rogers, Chris Nutting and Christine Harling.

NHS Connecting for Health and previously the NHS Information Authority provided support for the technical infrastructure. We would particularly like to acknowledge Gary Sargent and Sandy Garrity who provide helpdesk support to users.

We would also like to acknowledge David Cunningham for the initial design of the DAHNO application and Ronnie Brar for continued development and maintenance.

The analysis for this report was undertaken by the cancer registries and special thanks must be given to Andy Pring from the South West Public Health Observatory and Sandra Edwards from the Oxford Cancer Intelligence Unit, with the support of Ruth Jack and Henrik Møller at the Thames Cancer Registry.

We would like to acknowledge Patrick Bradley, Patrick Magennis, Andy Burns and Lynne Skyrme for their incisive and constructive comments during the report compilation.

Above all, we would like to thank the early adopters for the significant work carried out at the inception of the DAHNO Project and the users for their contribution which has enabled this first national annual report.

Foreword

I was delighted to be asked to write this foreword. The first DAHNO report represents an important milestone in the programme to collect and feedback information on all new cases of oral and laryngeal cancer. This programme for head and neck cancers, along with an equivalent programme for lung cancer (LUCADA), are the first two national clinical audits for cancer.

The work required to reach this point should not be under-estimated. Datasets have had to be developed and agreed, with common definitions for terms that cross cancer types. Information systems have had to be developed with the assistance of the NHS Information Authority - now the Information Centre. The audit is sponsored by the Healthcare Commission.

I would like to congratulate all those who have brought the audit to this point and in particular Richard Wight who has led the project. As the report shows, around one quarter of incident cases were reported in this first phase of audit (January 2004 to September 2005). The feasibility of the audit is shown by the fact that three cancer networks have reported the full number of expected cases and several others have reported substantial numbers of cases.

The challenge now is to ensure that head and neck cancer teams in all cancer networks participate. I am convinced that comprehensive comparative audit will drive up the quality of care for patients, leading to better outcomes.

Prof Mike Richards
National Cancer Director

An audit is solely dependent on contributions made by individual clinicians and their support staff across the country for it to be a success. This annual report represents the fruits of their labours, facilitated and supported by NHS trusts and cancer networks.

Peer commitment will hopefully act as a spur for others to join, and achieve the comprehensive and consistent coverage required to produce meaningful results.

This audit has significantly benefited from the knowledge and commitment of the National Clinical Audit Support Programme (NCASP) team, who have laid a sound foundation for future reports.

The first of many annual reports, it examines data submitted from the rollout up until September 2005. Organisations have joined at different points during this time period and more continue to do so.

This report describes the methods, results and themes arising so far. The completeness and comprehensiveness of submissions will increase over time, but this is an important landmark in a longer journey.

Richard Wight FRCS
Consultant Head and Neck Surgeon
DAHNO Project Lead

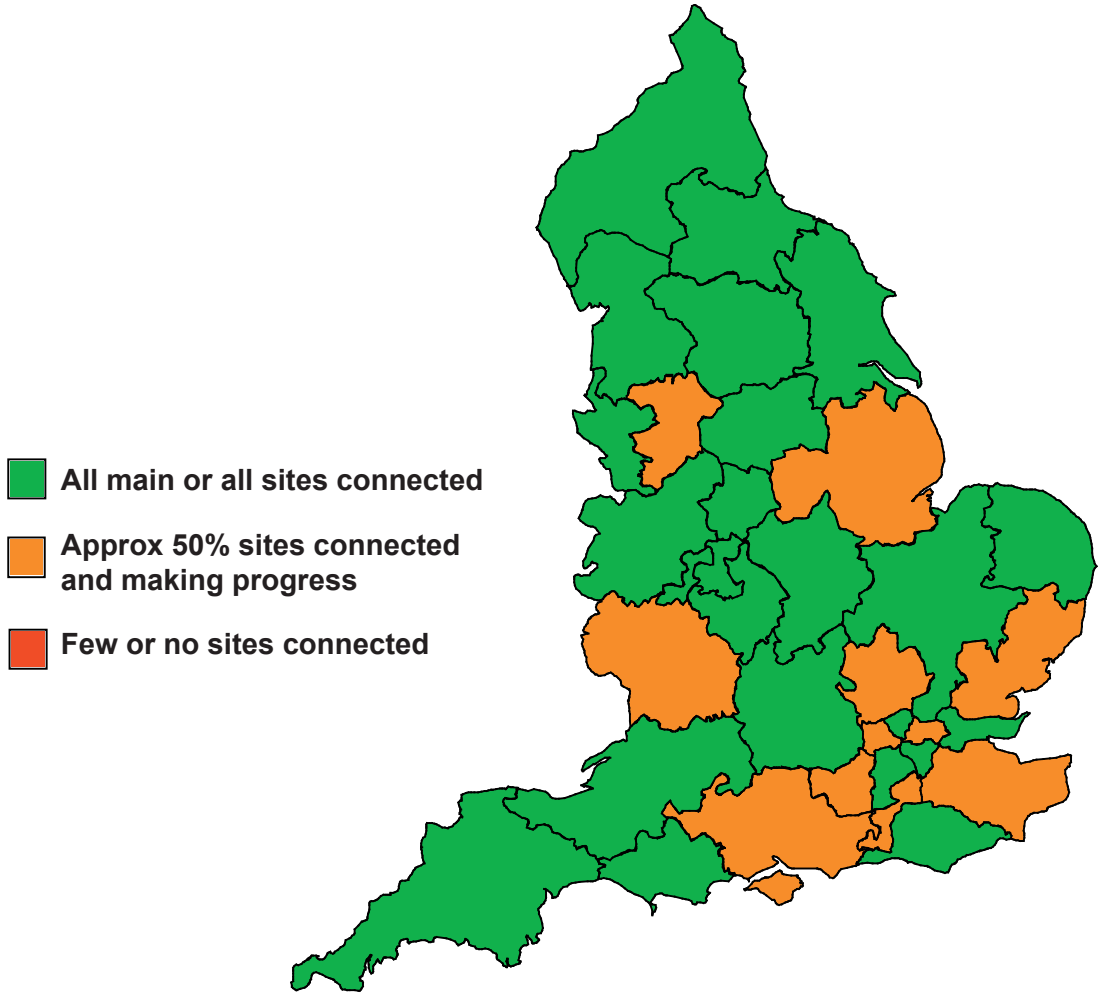
Contents

Maps of connected and contributing cancer networks

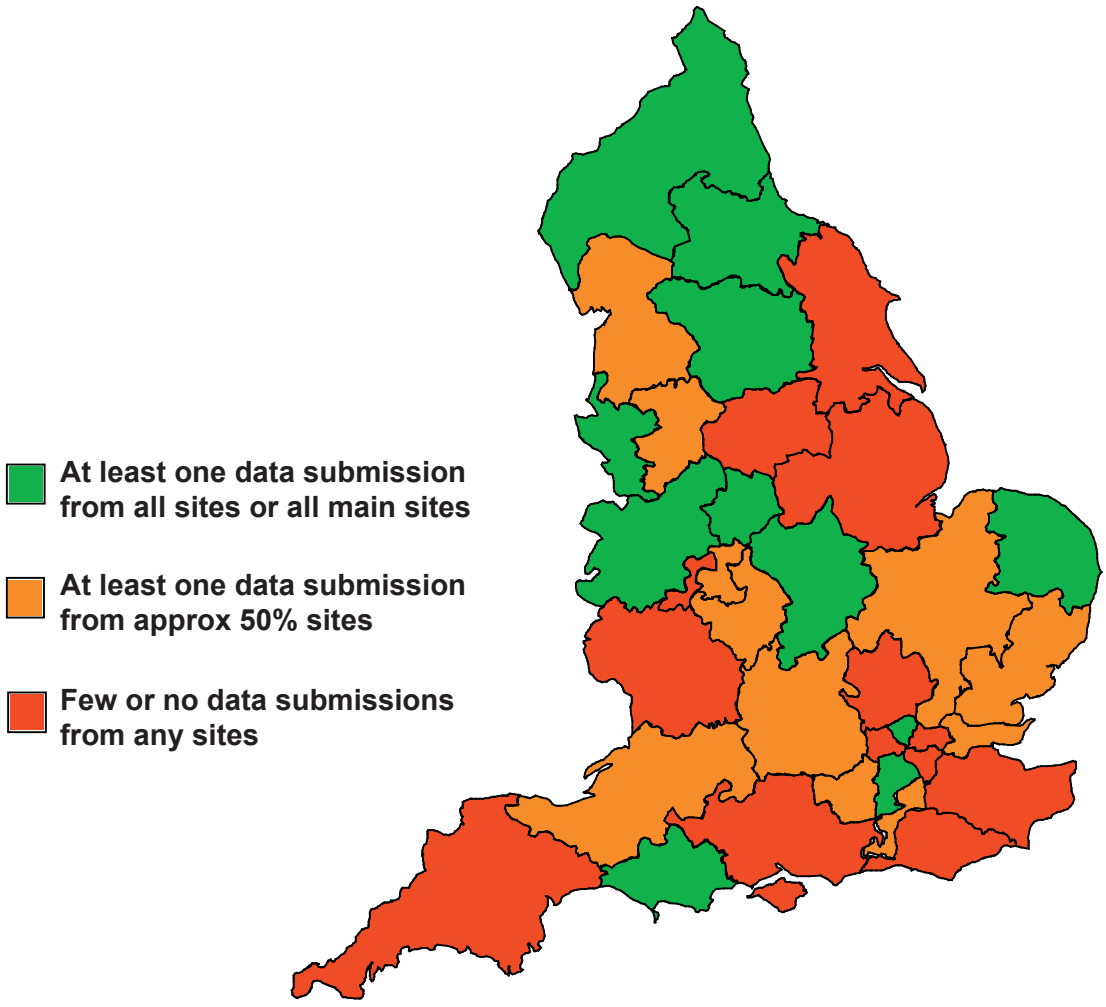
The following colour coded maps represent cancer networks in England that have connected to the DAHNO application or connected and submitted at least one patient record.

A breakdown of individual NHS trusts who have contributed to the audit can be found in Appendix 1.

Cancer networks connected to the DAHNO application as at end November 2005



Cancer networks submitting data to the DAHNO application as at end November 2005



SECTION 1.0 Executive Summary

The head and neck cancer audit, **DAHNO** (**Da**ta for **H**ead and **N**eck **O**ncology), has successfully provided a continuous electronic comparative audit on the management of head and neck cancer in England. The project has been supported by the relevant professional bodies and is sponsored by the Healthcare Commission.

The core issues addressed in the first phase of the DAHNO Project are:

- **Delivery of appropriate primary treatment (including adjuvant therapy) in the management of head and neck cancer affecting the larynx and oral cavity by a multi-professional team**
- **Delivery of care to agreed standards.**

Larynx and oral cavity cancer comprises approximately 50% of all head and neck cancer registrations in England. The disease burden of head and neck cancer is significant. Patients require intensive investigation, multi-modality treatments and prolonged rehabilitation with long-term support to achieve an adequate recovery.

Where head and neck cancer care happens - submission rates

The rollout of the head and neck cancer audit has occurred sequentially across England since January 2004 and each of the thirty-four cancer networks has had an opportunity to contribute.

Twenty-six cancer networks have submitted at least one patient record and the first annual report describes results for over 1,000 patient records.

Three cancer networks have managed to achieve high levels of registration with 100% of the expected case numbers recorded.

Results

Overview

The data in the first 18 months represents a proportion of cases (1,038 of an estimated 4,454), with data completeness varying for each patient record. Indicative findings and trends for data submitted to the audit are noted in section 8.0 of the report.

Who receives the care?

561 cases of larynx cancer and 477 cases of oral cavity cancer were submitted.

Cancer of the larynx and oral cavity, as anticipated, is a disease of older age groups (90% greater than 50 years old), with males predominating.

The patient journey

67.5% of patients were confirmed as having been discussed at a multi-disciplinary team (MDT) meeting. These results may reflect treatment decisions for some patients being made outside of MDTs, which is not in line with Improving Outcomes Guidance[40] where it is a standard that all patients are discussed at an MDT meeting.

Progression of a patient along the cancer care pathway requires prompt imaging. A significant number of patients' care, shows delay in diagnostic imaging.

The 62-day cancer wait target came into effect on 1 January 2006 (which is outside of the audit period) setting an expectation that patients referred under the two-week wait will commence treatment in under 62 days from referral. This audit shows that the median interval for larynx patients was 69 days, and for oral cavity was under 62 days. Considerable work remains to achieve this target for all patients.

Care provided

The first treatment in the majority of laryngeal cancer patients is radiotherapy, with a median commencement date, 49 days after diagnosis. For the smaller number who first undergo surgery, the median interval from diagnosis to operation is 30 days.

For the majority of oral cancer patients, surgery is the first treatment, with a median time to operation of 34 days from diagnosis. For the smaller numbers who undergo primary radiotherapy, the median commencement date of treatment was 49 days after diagnosis.

This suggests that head and neck cancer patients may have difficulties in accessing radiotherapy services, which may produce delays to treatment, but more comprehensive capture of radiotherapy data will help to clarify this.

Overall, head and neck surgery despite being complex, appears, from the information submitted, to be a safe procedure with few peri-operative deaths recorded.

The Expert Panel members noted that important aspects of caring for patients, i.e. dental assessment, speech and language therapy, dietetics and palliative care, could not be assessed owing to an absence of data.

Recommendations

The first analysis has demonstrated variability in record completeness between treatment centres and between individual records. Head and neck cancer teams should be encouraged to optimise data collection and submission. NHS Trusts and hospitals carrying out head and neck cancer care are to be encouraged to support this endeavour.

Summary report

A summary report is in preparation and will be issued by the end of May 2006. Its focus is for a wider audience beyond the professional head and neck community. It will be available on line at **www.dahno.com**

2.1 What is head and neck cancer?

Head and neck cancer describes a variety of neoplasms in the head and neck region. The definition excludes tumours of the brain and related tissues. Arising principally from the mouth (oral cavity), voice box (larynx) and throat / upper gullet (pharynx), head and neck cancers are amongst a group of the less common cancers, with approximately 7,000 new cases diagnosed in England each year[1].

The most common cancer sites are larynx and oral cavity, and more than 90% of all malignant tumours in the head and neck are squamous cell carcinomas (SCC) arising from the lining mucosa. There is, however, a wide distribution of other cancer sites and histologies providing a broad spectrum of disease.

Metastases from head and neck cancer occur in a significant number of cases with an orderly spread via the lymphatic system in the neck. Distant metastases occur less commonly[2]. Metastases from other cancers to the head and neck are rare[3]. Patients may present with more than one primary cancer[4,5].

The main contributory factors to developing head and neck cancer are tobacco, alcohol and a poor diet, and there is an association with living in areas of deprivation[6,7].

Common presenting symptoms include hoarseness, sore throat, difficulty in swallowing, and ulceration or swellings of the oral mucosa and tongue.

The majority of patients present with advanced disease, and provide a substantial and complex challenge to the managing team. Cancer of the head and neck inevitably has a substantial impact on patients.

2.2 Pathway of care

Head and neck cancer may be detected by general medical practitioners, general dental practitioners / community dental services, or through patient self-referral to hospital. Having entered the secondary care head and neck cancer treatment pathway, the patient can expect an out-patient appointment where an initial examination is performed and further diagnostic procedures ordered if appropriate. These may involve endoscopy, computed tomography, neck ultrasonography, magnetic resonance imaging, fine needle aspiration of any enlarged lymph nodes[8] and surgical biopsy of the lesion. The goal of diagnosis is to detect the presence of a tumour and to stage the cancer according to the International Union Against Cancer's (UICC) classification system[9].

Head and neck cancer treatment requires a wide range of expertise. In the UK, head and neck cancer treatment is organised around multi-disciplinary teams (MDTs). MDTs[10] may include: surgeons (ENT, maxillofacial, plastic surgery), clinical oncologists, health or social psychologists, dentists, nurses (Macmillan nurses, nurse counsellors), dieticians, speech and language therapists (SALT), physiotherapists, histo-pathologists, cytologists, radiologists, molecular biologists, social workers, epidemiologists, palliative care physicians and psychologists. MDTs hold regular meetings where the needs of individual patients are discussed and the appropriate care allocated.

Management of squamous cell carcinomas of the head and neck will depend on cancer site, stage and presence of nodal metastases (generally to the neck). Radiotherapy, surgery and chemotherapy are utilised in the treatment of head and neck cancer depending on the nature and extent of the disease. The patient can then expect regular follow-up appointments where their clinical status is assessed, with further diagnostic interventions as required. Patients will enter a rehabilitation pathway immediately following the initial treatment phase. In patients with incurable disease, a palliative regimen will be implemented.

2.3 Larynx and oral cavity - burden of disease

Cancer sites

The following anatomical cancer sites are covered by the head and neck cancer audit:

- Oral cavity: ICD-10 codes C02-C06 (buccal mucosa, lower and upper alveolus, lower and upper gingiva, hard palate, dorsal and inferior tongue, floor of mouth)
- Larynx: ICD-10 codes C10.1, C32.0, C32.1, C32.2, C32.8 and C32.9 (supraglottis (including lingual surface of epiglottis), glottis and subglottis).

Of the 216,702 cancers (excluding non-melanoma skin cancers) registered in England in 1998, cancers of the larynx (C32) accounted for 1,790 cases (0.83%) and cancers of the oral cavity (C02-C06) accounted for 1,628 cases (0.75%). These cancer registrations are more likely to be male (82% for cancer of the larynx and 59% for oral cavity)[1].

In the first phase of the audit, these two cancer sites were chosen for study because of their higher incidence rates relative to other head and neck cancers, and because they are relatively homogeneous in terms of aetiology and prognosis and have relatively clear anatomical definition. Thus, larynx and oral cavity represent approximately 50%[1] of all head and neck cancer registrations in England. It is envisaged, that in later phases of the audit, data on all head and neck cancers will be collected.

Impact of head and neck cancer on patients

The disease burden of head and neck cancer is significant. Patients require intensive investigation, multi-modality treatments and prolonged rehabilitation with long-term support to achieve an adequate recovery.

The impact of disease on functions such as eating, drinking, speech, swallowing and normal social interaction is significant.

Second primaries and locoregional recurrence in either the treated field or upper aerodigestive tract, mean that continued long-term surveillance is desirable.

Outcome in head and neck cancer

Cancers of the larynx and oral cavity are associated with significant mortality, for example, five-year survival for larynx cancer is around 50%. The cancer mortality to incidence ratio is the ratio of patients dying with that cancer in a year, to the number of new patients registered in the same year. For example, if the same number of patients died each year as new cancers were diagnosed, the ratio would be one, and if very few patients died, the ratio would approach zero. For all cancers of the larynx (C32), the ratio is 0.37 for males and 0.46 for females. The ratios for cancers of the lip, mouth and pharynx (C00-C14) are 0.44 for males and 0.41 for females[1]. These are comparable to ratios for prostate cancer (0.42) and cervix (0.41) and approach ratios for cancer of the colon (0.53)[1].

Better prognosis is associated with early detection, while late presentation and neck node metastasis drastically reduce long-term survival. The relatively poor survival prognosis for head and neck cancers is linked to lifestyle factors, co-existent comorbidity, late presentation and the high median age of incidence.

SECTION 3.0 Introduction to head and neck comparative audit

3.1 Measuring clinical care

Measuring clinical care has proven to be notoriously difficult. Variations in casemix and resource have confounded attempts to define good and bad practice. Establishing a national baseline is the first step towards defining existing care delivery. Improving Outcomes Guidance has defined a model of care delivery and 34 local delivery plans (LDPs) are currently being defined. National audit provides us with the tools to assess compliance with these defined standards and identify resource limitations. Measuring clinical care is more than ticking boxes to achieve compliance. It should include a local re-appraisal of care delivery methods, and the ability to compare local standards and nationally derived figures is a significant advance.

3.2 Sources of existing information and differences that the head and neck cancer audit provides

Collection of head and neck cancer data in the United Kingdom has evolved from individual committed clinicians' personal recording of patient cases, and cancer registries meeting statutory requirements. The latter, until recently, has lacked stage information, and this has hindered production of outcome and stage-adjusted survival data.

Individual institutions' case series and reporting of treatments have lacked comprehensive cover and multi-organisational comparison.

At first sight, the data collection method used by the head and neck cancer audit and the cancer registries appears opposite and exclusive. Cancer registries currently collect selected data on all cancer patients, their tumours and tumour characteristics (pathology, stage), treatment category and outcome. Since cancer management takes place in many locations and the initial treatment episode may take months, most registries make a single data extraction (or collation in the case of electronic registries) several months after diagnosis, in order to avoid repeated access of the clinical record.

The head and neck cancer audit on the other hand, continuously collects data at each patient service contact, and this record is continually updated. Clinical aspects of staging and other casemix factors can be more easily collected.

It is hoped that mechanisms facilitating the collection of data for the head and neck cancer audit will enable easier and better quality data capture for cancer registries.

Given the significant resource requirements of patients with head and neck cancer, the first phase of the national audit has focused on the process and delivery of multi-disciplinary assessment. There is a need to collect data to more accurately reflect the healthcare burden imposed by head and neck cancer.

With time this data will allow national assessment of outcomes and provide a tool to improve standards of care, identifying areas of good practice to the wider group of teams delivering head and neck cancer care.

3.3 Randomised controlled trials (RCT) and meta-analysis in head and neck cancer

The gold standard of evidence in assessing the efficacy of different therapies is a randomised controlled trial or a systematic review of a number of randomised trials, with specific statistical methods employed (meta-analysis).

In head and neck cancer, the complexity of the disease and its treatment has meant that very few randomised trials exist or are likely to be performed. Meta-analyses, such as the application of chemotherapy[11], have only been published on specific areas of treatment.

The head and neck cancer audit will help fill this void of evidence by building a high quality clinical database (HQCD) from consecutive cases. This database will provide both comprehensive and accurate information, including recording patient details that affect outcome. With sufficient data on confounding variables, risk-adjusted comparisons can be made. The ensuing large volume of data allows sub-group analysis, which in turn allows true comparison of the specific extent of disease and not just of aggregated disease status. HQCDs also facilitate local audit and comparison to peer and are a cost-effective means of wide-scale clinical engagement[12].

3.4 The need for comparative audit in head and neck cancer

During the 1990s, recognition developed amongst head and neck cancer professionals, that the absence of accurate systematic prospective data collection was a major obstacle to improving care standards in the United Kingdom. In 1999, BAHNO produced a dataset template for head and neck cancer[13]. This dataset used standardised coding, to allow it to integrate with both data capture in NHS organisations and cross comparisons between different organisations and specialties managing head and neck cancer. The dataset also met many of the requirements that have subsequently been utilised across other cancer sites in the formulation of the National Cancer Dataset (NCDS). The dataset sought to record the minimum amount of data required, to allow patient characteristics and management to be identified, and patient outcomes to be quantified.

The latest versions of the dataset and supporting manuals can be found at **www.dahno.com**

The importance of timely delivery of care has been enforced by the introduction of waiting time targets, initially from referral to first appointment 'two-week wait', and for head and neck cancer from 1 January 2006 from referral to first treatment (62 days) and from decision to treat to first treatment (31 days).

In 2002, BAHNO agreed to join forces with the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons (RCS) of England, the National Clinical Audit Support Programme (NCASP) within the NHS Information Authority (NHS IA), the Department of Health (DH) and the cancer registries to deliver a national comparative audit based upon the NCDS sub-set for head and neck cancer. The project, called **DAHNO** (**Da**ta for **H**ead and **N**eck **O**ncology) which manages the head and neck cancer audit, has provided both a technical infrastructure for data collection across England as well as facilities for local and central data analysis to deliver a continuous comparative audit on the management of head and neck cancer. The project has been supported and is sponsored by the Healthcare Commission.

There are a number of key areas relating to head and neck cancer, which, if properly addressed, would be likely to have an impact on the incidence and outcomes of the disease.

These can be summarised as follows:

i) **Prevention (e.g. reduction in cigarette smoking and alcohol consumption)**

ii) **Earlier presentation of patients to secondary care (including screening)**

iii) **Timely and appropriate referral from the 'diagnostic' team to the 'therapy' team (including process of staging)**

iv) Management by multi-professional specialist teams

v) Consistent standards and patterns of treatment

vi) Timely access to treatment.

Multi-professional management is recognised as the gold standard, bringing substantial benefits. There is good evidence however of widely differing standards of care between different parts of the UK and even within the same region, but as yet no comprehensive mapping of care delivered has occurred. Patterns of care delivery vary and a variety of different specialties provide care. The Improving Outcomes Guidance was produced by the National Institute for Clinical Excellence (NICE) in 2005, and it is timely that there is now a national comparative audit to better understand current provision as well as to provide a yardstick to measure the impact of change.

A previous audit by BAHNO has confirmed variation in management across geographically similar areas, and a variation in outcome. Reasons for this are unclear and could relate to a number of different factors:

- Differing standards of clinical practice
- Differing levels of comorbidity
- Differences in stage of disease at presentation
- Variations in access to specialist treatment services
- Artefacts of analysis methods in calculation of the population 'denominator' when deriving the treatment 'proportions'.

If we could match the outcomes from the districts with the lowest rates to those with the highest, we would probably be able to significantly improve the long-term survival rate in head and neck cancer without any advances in therapy.

Initially, the head and neck cancer audit has focused on adherence to pre-determined process standards. In time, it is hoped that the head and neck cancer audit will have sufficient power to allow examination of the relationship between standards of care and patient outcomes such as mortality.

Timeliness of treatment reflects a number of different aspects of care delivery, but is likely to be influenced in part by the resources of the service both in terms of equipment and manpower.

The core issues addressed in the first phase of the DAHNO Project are:

- **Delivery of appropriate primary treatment (including adjuvant therapy) in the management of head and neck cancer affecting the larynx and oral cavity by a multi-professional team**
- **Delivery of care to agreed standards.**

3.5 Key partners in developing clinical audit

Audit and the Healthcare Commission

The long-term objective for the Healthcare Commission is to ensure that each level of the NHS, including individual clinicians in primary and secondary care, clinical teams, Acute and

Primary Care Trusts (PCTs), the Department of Health (DH), the Healthcare Commission, the National Institute for Clinical Excellence (NICE) and the public have access to accurate and complete risk-adjusted comparative clinical audit data. The data will be used to support monitoring quality and performance against agreed clinical standards and benchmarks, whether contained in National Service Framework (NSFs), by NICE or other national guidance.

NHS Cancer Plan and cancer audit

The NHS quality agenda requires services to monitor quality of care delivered in a systematic way through clinical governance. Capacity to undertake clinical audit to monitor the quality of clinical care, specifically using national risk-adjusted clinical audit data, is a key component of clinical governance.

The Government is committed to introducing national comparative clinical audit to monitor clinical performance against agreed standards and indicators.

One of the key commitments of the NHS Cancer Plan is to bring survival rates up to the best in Europe. Achievement of this objective will depend critically upon:

- Ensuring that patients are diagnosed and treated without unnecessary delays
- Ensuring that patients receive optimal treatment, especially the initial treatment package given after the diagnosis of cancer.

Implementation of the cancer waiting times dataset, (September 2003 for head and neck cancer) provides information on timeliness of treatment. However, current information and monitoring arrangements do not provide direct information on the appropriateness of treatment. To determine this, anonymised data on individual patients needs to be collected and analysed.

NCASP

There are three national clinical audits in cancer, (head and neck, lung and bowel), managed by the National Clinical Audit Support Programme (NCASP) within the NHS Health and Social Care Information Centre (NHS HSCIC). These audits, together with audits in coronary heart disease and diabetes, were originally commissioned by the Department of Health (DH) through the NHS Information Authority (NHS IA), the predecessor of the NHS HSCIC, but are now commissioned by the Healthcare Commission.

For the national head and neck cancer audit, NCASP works directly with representatives of the British Association of Head and Neck Oncologists (BAHNO) who provide the clinical direction and specialist clinical input.

Following wide consultation on the audit proposals and subsequent system development and testing, the audit was formally launched in 2003.

It is anticipated that the Healthcare Commission will fund this and other cancer audits for a further three years until March 2009.

3.6 Key reports in improving cancer care

The Calman-Hine report, A Framework for Commissioning Cancer Services published in 1995[14], identified inequities in service provision for cancer patients and the resultant variable outcomes. The report emphasised the importance of monitoring and auditing the quality of service provision, a theme emphasised by the National Cancer Plan published by the Department of Health in 2000[15]. As a result of these reports, a National Cancer Dataset (NCDS)[16] was developed by the National Health Service Information Authority (NHS IA), to assist cancer service providers in the sharing of data across all healthcare boundaries and to support patient care and comparisons of cancer information. The NCDS assists in assessing:

- The provision of high quality care for individual patients
- The delivery of clinical governance, ensuring that the care received by groups of patients is in line with national guidance and achieves the best possible outcomes
- Performance management, which ensures that national targets (e.g. for waiting times) are achieved
- Public health and inequalities reduction
- The monitoring of incidence trends, survival and mortality at a population level.

3.7 National Institute for Clinical Excellence (NICE) Improving Outcomes Guidance (IOG) for head and neck cancer

Clinical guidelines are recommendations by the National Institute for Clinical Excellence (NICE) on appropriate treatment and care of individuals with specific diseases and conditions within the NHS. They are based on best available evidence. Guidelines aim to help health professionals in their work, but they do not replace their knowledge and skills.

Good clinical guidelines aim to improve quality of healthcare. They can change processes of healthcare and improve outcomes by:

- Providing recommendations for treatment and care of people by health professionals
- Using them to develop standards to assess the clinical practice of individual health professionals
- Using them to educate and train healthcare professionals
- Helping patients to make informed decisions, and improve communication between patient and health professionals.

NICE commissioned the National Cancer Steering Group to develop service guidance on head and neck cancer for NHS use in England and Wales. The guidance was published in 2005 and provides recommendations for good practice that are based on best available evidence of clinical and cost effectiveness. The guidance can be found at **www.nice.org.uk/page.aspx?o=233550**

The areas addressed, include head and neck cancer network and multi-disciplinary teams (MDTs), referral, diagnosis and assessment, treatment services, post-treatment follow-up and care, prevention and awareness, patient centred care and palliative care.

Presently, Improving Outcomes Guidance (IOG) action plans, from each of the 34 cancer networks in England, are being reviewed by the Department of Health (DH) with a view to implementation over the next three years.

3.8 Annual Health Check

The long-term objective for the Healthcare Commission, as described above (section 3.5), is to ensure that each level of the NHS and the public have access to accurate and complete risk-adjusted comparative clinical audit data. The data will be used in the Healthcare Commission's Annual Health Check of NHS trusts to support monitoring quality and performance against agreed clinical standards and benchmarks, whether contained in National Service Framework (NSFs), National Institute for Clinical Excellence (NICE) guidelines or other national guidance.

It is anticipated that, in the first instance, a simple measure of participation in the head and neck cancer audit will be used in the assessment of trust declarations. This will move in time to the use of measures of case ascertainment and data quality, to demonstrate appropriate levels of engagement in the audit, and other more specific indicators of care.

3.9 Other stated / published clinical standards used as benchmarks

Standards are precise authoritative criteria to ensure a process is fit for purpose. They are created with the co-operation of, and consensus from, professionals and patients, or general approval of interested parties. Based on consolidated findings of evidence and experience, they are aimed at promoting optimum benefit as well as approval / sponsorship of a professional national body.

Standardisation improves efficiency by delivering service consistency; it aims to avoid geographic variation.

Standards are an essential component for audit, bench-marking and accreditation / certification / designation of cancer provision.

In 2001, a consensus group of practising clinicians, supported by the British Association of Head and Neck Oncologists (BAHNO), published practical care guidance for clinicians participating in the management of UK head and neck cancer patients[17]. It proposed a series of quality objectives.

The consensus guidance from the British Association of Otolaryngologists / Head and Neck Surgeons throughout its iterations (1998 to 2002)[18,19,20], reviewed current standards, and sought to determine consensus standards of service delivery and aspects of care along the head and neck pathway, to promote a common framework of delivery. The process was the result of extensive patient and carer discussion based on the South West Head and Neck Audits (SWAHN 1)[21]. Where professional and patient / carer standards disagreed significantly, the patient / carer viewpoint was taken as the default position. No formal monitoring of the uptake or acceptance of these standards across England has occurred.

In 2001, the NHS sponsored a 'proposal generating event' consisting of multi-disciplinary head and neck groups from across England to describe what an ideal head and neck service would look like. This was used as a basis to develop the Improving Outcomes Guidance subsequently published in 2005[40].

4.1 DAHNO application

The head and neck cancer audit application (known as DAHNO - **Da**ta for **H**ead and **N**eck **O**ncology) uses IBM Lotus Notes® and IBM Lotus Domino® as constituents for its software infrastructure. IBM Lotus Notes® and IBM Lotus Domino® are industry leading, client-server, collaborative document-management products incorporating robust security features, and have been widely adopted for use in the commercial sector.

Use of the DAHNO application requires connection to NHSnet. It is installed by an auto-install CD with minimal local IT system changes required.

IBM Lotus Notes® allows documents to be defined for data entry and display and treats collections of documents as 'databases'. Each document can be populated with all the design elements familiar to web users.

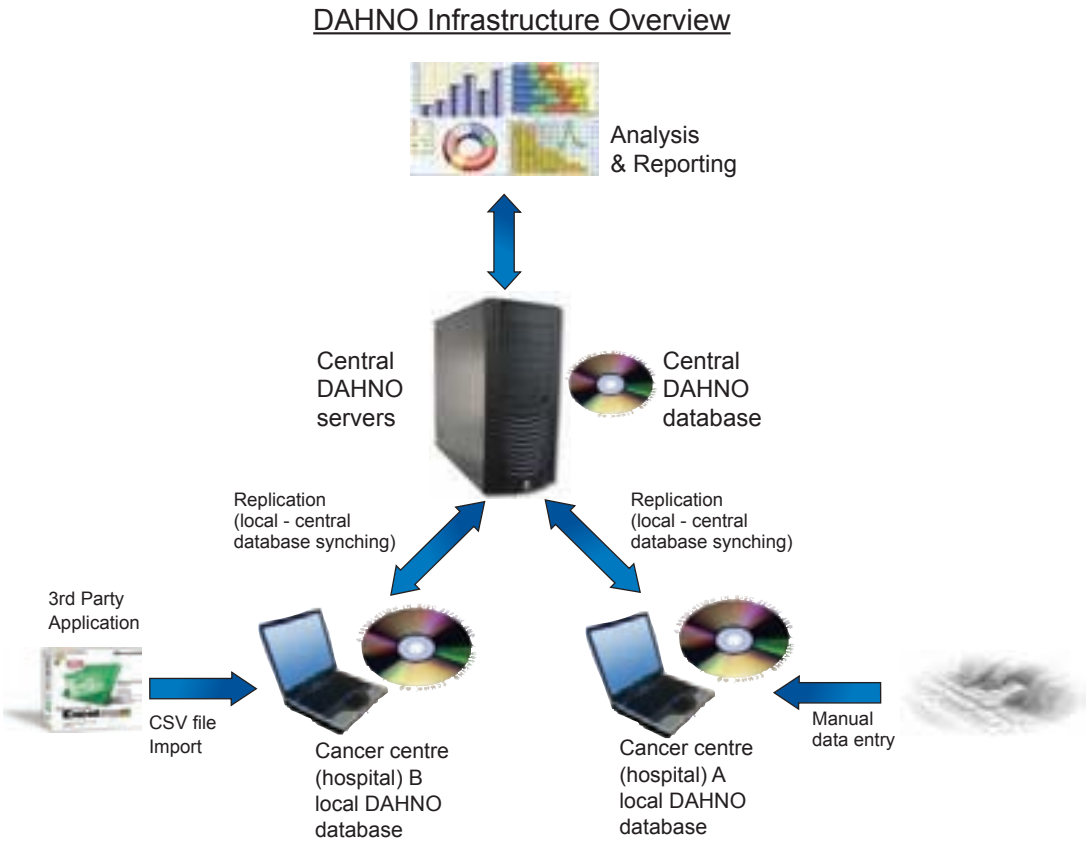


Fig 4.1a

Each hospital accesses its own local encrypted replica of the DAHNO application database so that the DAHNO application response times are not subject to any network delays.

Opening a database allows users to see all documents to which they have authorised access, and in turn allows creation of new documents, (either by directly keying-in data or by importing data from a third-party supplied data file), or editing of existing information.

Once data has been entered into the cancer centre's local DAHNO application database, the database is then synchronised with the central DAHNO application database so that

data can be analysed, and subsequently reported on. The application requirements and recommendations can be found in Appendix 2.

4.2 DAHNO application security and patient confidentiality

DAHNO application security

Security mechanisms are designed to ensure only authorised users access information on the DAHNO application database. Users only see records submitted by their own organisation (unless permission is given for them to view other organisations' data from other trusts / cancer networks), and published information contains only comparative analysis figures. Several levels of security are built into the system:

- ID security: the DAHNO application is accessed through use of an IBM Lotus Notes® ID, and that ID can be set to expire or have its access terminated, thus preventing unauthorised users from accessing the system. A complex password is required to access the IBM Lotus Notes® ID (and thus, the DAHNO application itself) and that password can be set to expire after a given period forcing the user to change it regularly.
- Server security: the central (server-based) DAHNO application database replica is also protected by server security so that no unauthorised persons can obtain access to it or replicate data to it.
- Application security: access to the IBM Lotus Notes® database is controlled by a database Access Control List (ACL). This ensures both non-repudiation, (a user cannot deny that they have accessed data), and that users and organisations only have access to their own records. Users may be given 'read only' or editing rights. Users can delete records if they have the correct permissions and if there are no child documents relating to that record.

The application is also encrypted so that if any unauthorised person were to somehow obtain the hard drive upon which the DAHNO application exists, they would also need an authorised ID file (and knowledge of its password) to access it.

All system database accesses are recorded in a system log file that can be audited in the event of suspected security threats or data misuse.

Patient confidentiality

Audit data is subject to strict rules of confidentiality. The National Clinical Audit Support Programme (NCASP) continues to work with the Healthcare Commission and the Patient Information Advisory Group (PIAG) to ensure that support is provided under Section 60 of the Data Protection Act for the collection and use of patient identifiable data. All current NCASP audits have PIAG support.

Cancer centres send the data to the DAHNO application via a secure connection to the NHS secure network, (NHSnet), where it is securely stored on a highly encrypted national computer database. This process is very secure. Once captured, the data is only accessible to people who store and analyse the data. Patients can choose to opt-out of the audit, such that their details will not be stored or used for any purpose by the audit.

SECTION 5.0 Methods and approaches

5.1 Methodology

A generic methodology in common with other National Clinical Audit Support Programme (NCASP) cancer audits was followed, to include the following items:

- Establishment of, and agreement to, the main questions the project would address derived from the aims of the National Cancer Framework (NCF)
- Establishment of data items needed to answer the specified issues (a sub-set of the National Cancer Dataset (NCDS))
- Agreement of a project plan and timetable (including funding issues, roles and responsibilities of partner organisations and process for recruitment and support of participating centres)
    - Development of a model for the process(es) of local data collection, central collation and analysis (including issues of security and confidentiality, to meet Caldicott Guardian requirements)
    - Development of methodology for quality assurance of data
    - Development of interfaces / messages followed by notification of specifications to system suppliers, modification of software packages accordingly and rollout to users
    - Definition of processes to oversee data collection, transmission and collation on a day-to-day basis.
- Responsibilities for data analysis and interpretation (including such issues as levels of access)
- Reporting format, timing and procedures.

5.2 Clinical aspects

Inclusions in the head and neck cancer audit phase I

In planning and deploying the DAHNO application, it was recognised there was a need for local organisations to commit resources to enable regular and timely collection of data. The scope of the first phase, (by limiting collection to squamous cell carcinomas of the larynx and oral cavity), hoped to allow good case acquisition, whilst keeping the burden of data collection to manageable proportions. In later phases, it is envisaged that data from all tumour types and sub-sites will be collected.

Using the relevant National Cancer Dataset (NCDS) elements, the DAHNO Project Team aimed to identify the following details from contributory centres:

- New primary cases of squamous cell head and neck carcinoma involving **the larynx and oral cavity**
- The **patients diagnosed with head and neck cancer (larynx and oral cavity) by cancer network** (and their component trusts and cancer centres) across England and their route of presentation (e.g. two-week wait, routine referral etc), in each case to use a population denominator (or close) derived via the cancer registries. This needed to reflect both workload and distribution of cases
- **Decompensation from comorbidity at diagnosis**

- Whether management of cancer patients **has been by an identified multi-disciplinary team (MDT) and to agreed standards with equity of care and without undue dela**y
- The **primary treatment modality(ies) received (including adjuvant therapy) for larynx and oral cavity** including surgical resection, radical and palliative radiotherapy, chemotherapy, specialist palliative care and supportive care
- **Disease eradication**
- **Head and neck cancer specific mortality rate and age-specific corrected survival.**

Exclusions in the current phase of the head and neck cancer audit

Exclusions in phase I of the head and neck cancer audit are:

- Cancers in anatomical cancer sites outside the larynx and oral cavity
- Carcinoma in situ of the larynx and oral cavity
- Non-squamous carcinomas and secondary carcinomas to the head and neck
- Secondary treatment modalities for recurrent disease
- Adverse events.

Casemix factors

The head and neck cancer audit examines key casemix factors in detail for the first time on a large scale. Data collection has historically been poor with regard to many of these factors which are crucial to the debate. The key factors considered are:

- Age and sex
- Comorbidity
- Performance status
- Stage at presentation and time of treatment decision.

Part of the NCDS development was to identify a robust, meaningful and user-friendly comorbidity scale. No such scale is universally accepted. The Adult Comorbidity Evaluation scale - ACE-27[24] (see appendix 6) has been validated in both the USA[25] and in Britain[26] and has been applied to adults with head and neck cancer. A patient's self administered questionnaire is available and allows rapid collection and collation of an integer score (0,1,2,3).

Within the care pathway of patients with head and neck cancer, diagnostic services have a significant impact on timeliness both in diagnosing and treating cancer centres. They are key potential bottlenecks that determine the pace at which individuals can progress to commencement of treatment.

A questionnaire was distributed on joining the head and neck cancer audit, to assess local access to services as well as to specialist diagnostic and treatment services, such as the number of local CT and MRI scanners, specialist radiologists, specialist histo-pathologists, surgeons, oncologists and palliative care consultants etc. The aim is to maintain this throughout future phases of the audit.

Putting all these aspects together, it should be possible, therefore, to determine at least the major likely causes of inter-district variations in treatment for the first time. This information can then be used by cancer networks to assist in supporting, developing and resourcing local head and neck cancer services.

5.3 Determining cancer centres: trusts managing head and neck cancer

Lead clinicians and managers from all 34 English cancer networks were contacted and asked to provide the names of NHS trusts that provide either diagnosis only or diagnosis and treatment to patients with head and neck cancer.

From the replies received, 189 cancer centres (and their associated trusts) have been identified as contributing care to head and neck cancer patients. Subsequently the number of trusts submitting has reduced as some organisations have combined for purposes of submission. This will continue to be adjusted over time with any rationalisation of teams.

Each of these organisations were contacted by a joint letter from the DAHNO Project Chair and the Healthcare Commission and invited to contribute. They were subsequently invited to attend sub-national training sessions.

5.4 Head and neck cancer audit rollout

The early adopter phase took place between November 2003 and February 2004. Recruitment for early adopters began in June 2003 via an informal tender process; 18 applications were received, and based on predetermined selection criteria, 14 cancer sites were chosen to receive small scale support funding from the following cancer networks:

- North London
- Northern
- West Anglian
- Arden Cancer
- Avon Somerset and Wiltshire.

An early adopter phase evaluation day was held on 24 February 2004.

In April 2004, a letter was sent to trust Chief Executives as an advance notice of rollout. It invited trusts to ensure relevant people were aware of, and made necessary preparations to participate in the audit, which commenced a phased rollout across England during May to December 2004.

To rollout the head and neck cancer audit, the DAHNO Project Team undertook the following:

- Contacted user and IT contacts in each of the 34 cancer networks and 189 cancer centres in England who were engaged in head and neck cancer diagnosis or treatment to notify them of the rollout timescales
- Generated interest in the system via road shows available to a key hospital contact in each of 34 cancer networks
- Carried out training of IT / user personnel in the key contact hospital to install and operate the DAHNO application
- Obtained user details for preparation of certificate IDs (started one-month ahead of installation) as specified in helpdesk arrangements
- Set up a DAHNO Helpdesk for technical and clinical queries.

Following rollout, non connection has been pursued by verbal, email and written contact to encourage participation, which will continue until we meet the Healthcare Commission expectations of 100% participation.

5.5 Patient sample identification

Participating teams were asked to include prospectively all identifiable new primary cases of squamous carcinoma of the larynx and oral cavity (L+OC) seen in their institution / network as appropriate.

For larynx, this comprises: cancer sites ICD-10 codes C10.1, C32.0, C32.1, C32.2, C32.8 and C32.9 (supraglottis (including lingual surface of epiglottis), glottis and subglottis) and for oral cavity: cancer sites ICD-10 codes C02 -C06 (buccal mucosa, upper alveolus and gingiva, lower alveolus and gingiva, hard palate, tongue (dorsal and inferior) and floor of mouth).

These are identified from a range of sources:

- MDT meetings
- Urgent two-week wait rule referrals and other clinic booking systems
- Pathology reports
- Hospital patient administration systems (PAS)
- Death certificates (via cancer registries and / or Office of National Statistics (ONS))
- Any other records maintained by members of the local head and neck cancer team.

5.6 Data standards

The audit dataset has been submitted to the Information Standards Board (ISB) for approval and has received conditional approval at 'full standard'. It is anticipated that satisfaction of the conditions will lead to the publication of a Dataset Change Notice (DSCN).

5.7 Priority outputs and rationale

The following are the major end points for analysis (and are further described in Appendix 4 as 'first priority' outputs and shown in bold below):

1 Demographics and casemix: ***{outputs 1.1 - 1.6}***

Number of patients with new head and neck primaries of the larynx and oral cavity (L+OC) per year by age, sex and stage:

- Percentage completion of staging and recording of stage prior to treatment planning by sub-site
- Percentage having pre-treatment measure of comorbidity and performance status
- The effects of socio-economic status on diagnosis, treatment and outcome.

2 *Waiting intervals and source of referral:* ***{outputs 2.1 - 2.15}***

- Source of referral to specialist team including ratio of primary to secondary care, and of those, the number presenting under the two-week wait rule
- Waiting intervals from first symptom to first referral
- First referral to the specialist team to first out-patient visit
- First referral to diagnosis
- First referral to first definitive treatment.

Within the pathway this will include:

- Interval from request to reporting of imaging (CT / MRI) contributing to pre-treatment staging and cancer care planning
- The types of imaging performed
- Consideration of intervals from taking of specimens for histological examination to reporting.

3 *Increasing the proportion of patients with squamous cell carcinoma of the larynx and oral cavity who receive appropriate specialist opinion and treatment. Examples* ***{outputs 3.1 - 3.12 larynx, outputs 4.1 - 4.12 oral cavity}*** *as measured by:*

- Percentage of patients discussed in a multi-disciplinary team (MDT) meeting prior to commencement of treatment, and assessment by a dietician and speech and swallowing therapist and appropriate dental assessment pre-treatment
- Percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing curative surgery by type of procedure and by age, stage, comorbidity and access to specialist surgical expertise
- Percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing resective surgery by type of clearance of surgical margins obtained, by sub-site
- Percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing radical radiotherapy by age, stage, comorbidity and access to clinical oncology expertise and linear accelerator / simulator time
- Dose and regimen (including continuous hyper fractionated accelerated radiotherapy (CHART), teletherapy and brachytherapy) of radical radiotherapy used in these patients by age, stage, comorbidity and access to oncology expertise and equipment
- Percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing chemotherapy by age, stage, comorbidity and access to oncological expertise
- Percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing post-operative primary cancer site and neck irradiation
- Percentage of all squamous carcinoma of the larynx and oral cavity cancer cases referred to the specialist palliative care team.

4 *Monitoring the improving outcomes of patient care:* ***{outputs 5.1 - 5.5}***

- Survival at 12, 24 and 60 months (extending to longer periods as the project progresses) in each of the sub-groups by centre
- Locoregional recurrence within one year and two years (by treatment and tumour type).

5 *Clinical Trials:* ***{output 6.1}***

- Percentage of patients with squamous carcinoma of the larynx and oral cavity entered into national clinical trials following diagnosis.

6.1 Cancer centre identification

Information on hospitals that provide head and neck cancer care was identified by correspondence with cancer networks to draw up a definitive list. This highlighted a number of small cancer centres that provide head and neck services, but have their data submitted via an adjacent organisation. Records of participation were appropriately amended. Throughout the audit it remains important to maintain an up-to-date log of which institutions provide head and neck cancer care and from where their data will be submitted.

6.2 Design

The design for the DAHNO application was an iterative process between developers and the DAHNO Project Team. The early adopter phase identified a number of errors in both content and presentation, which led to application modifications on an ad hoc basis and subsequent updating of the support manuals. The diligence of the early adopters must be acknowledged.

Feedback from users and initial preparation for reporting identified an unexpected error in the imaging section which has impacted on the proposed output 'percentage having chest imaging by chest x-ray or CT scan prior to cancer careplan'. The field recording the anatomical examination was originally created as a single entry field. For example, where a CT scan covered neck and thorax, entering data for both cancer sites required two separate imaging records or the selection of only one cancer site. Following identification, this has now been corrected, and converted to a multiple entry field. As a consequence, the above output has been invalidated and therefore, although reported, it cannot be reliably assessed in this year's report.

Continued feedback from users has led to a number of other ad hoc modifications. However, now that 'design stability' has been achieved, any future corrections or changes will be made on a batch basis with agreement and specification by the User Group and advance notice to users.

6.3 Data submission

Data can be submitted to the DAHNO application via direct data entry, which accounts for about two-thirds of the data, or by uploading from a local third-party system. Data submission, by uploading from third-party systems, requires the construction of csv export files. Producing the csv files for the first time is a tedious process, but once established, it provides a continuous means for submission. The file contains data in a strict sequence and setup. The DAHNO Project Team have found problems (e.g. the automatic addition of an additional column) with the export functions of some suppliers' systems and will continue to work with third-party suppliers to try to facilitate the transfer of data.

6.4 Comprehensive submission

From the log of organisations providing head and neck cancer care, direct contact from the DAHNO Project Team has been made to establish reasons for both non-connection and non-submission. The DAHNO Project Team, in partnership with the Healthcare Commission, cancer networks and head and neck professional bodies, will encourage all organisations that are yet to submit any data, to achieve this during 2006.

6.5 Submission completeness

The first analysis, as identified in this report, has demonstrated variability in record completeness between cancer centres and between records. In preparation for the next report, the DAHNO Project Team has now instigated additional support and system reporting, to provide better identification of areas for improvement to users to raise completeness. Regular workshops will focus on amplifying both the processes of data collection and common areas of poor quality and completeness.

6.6 Analysis

The analysis of a series of multiple fields from a relational database is a complex task, undertaken by the cancer registries and the DAHNO application developer. Numerator and denominator definition has iteratively supported this, and a methodology has been established for consistent future comparisons. For future reports, it will remain a challenge to analyse data by cancer network, particularly where boundaries and patient treatment pathways may vary, and to understand its limitations and interpretation.

6.7 Data quality

The reference to hospital name / number in the import key, (used to relate patient data already existing in the database with that being imported), needs to be changed for all types of DAHNO application data records, to avoid duplicate records being created, when one hospital submits data on behalf of another hospital.

6.8 Data cleansing

Within the DAHNO application, data cleansing, where otherwise meaningless or unrecognised values can be automatically corrected during the import process to reflect valid data entries, has yet to be applied.

6.9 Importing errors

Reporting import errors to users needs to be improved, and we also need to centralise hospital logging reports so that they can be fully analysed.

At present, restrictions apply in importing resective pathology details from cancer centres using csv export into the DAHNO application.

6.10 Exporting data

Work is in progress to define, agree and implement a data export strategy for data collected on the DAHNO application.

The current analysis of data contains a sample of cases from hospital trusts across England.

The majority of reported measures are presented either as a count or percentage. Notes accompanying each measure seek to make the basis of each calculation clear.

Both presentations are affected by completeness of patient records:

- Counts are the total number of records (usually of patients) in the DAHNO application data extract with a specific record value, or in some cases a count of records with a non-blank value for a particular field.
- The calculation of percentages involves a count and a denominator. The choice of denominator is complicated by completeness of records. For certain measures with percentage calculations, the selected denominator is the total number of registrations. For others it has been more appropriate to use the total number of non-blank records.

The quality of any data analysis is dependant upon the ascertainment, completeness and quality of the data submitted to the DAHNO application. Analysis is based purely on the data submitted to the DAHNO application by contributing trusts. It may be important to recognise that because many records are incomplete, the published information is based on fewer than the total number of registered cases. This applies to some of the interval calculations which summarise an analysis of multiple fields, e.g. Figure 8.4.5.4a and b: Interval to first treatment by stage.

No attempt has been made to analyse the statistical significance of any results. Data is published as a simple description of data gathered during work-in-progress. As the quantity and quality of data improves, more sophisticated analyses will become possible.

The data for analysis was extracted from the DAHNO application as a collection of text files (csv format). Initial analysis of this data was carried out using Stata® 8.1, with the final analysis completed using Stata® 8.1, Microsoft® Excel 2000 and Microsoft® Access 2000. The initial effort invested to write a series of analytical routines for Stata® 8.1, made repeat analyses easier during the initial data analysis, and may be of use for future reports.

8.1 Introduction

The following analysis was performed by the cancer registries on data extracted from the DAHNO application database in accordance with the Data Analysis for Annual Report Specification v0.9 November 2005, supplied to the cancer registries by the DAHNO Project Team. The data extract period includes patient records with a 'date of diagnosis' between January 2004 and September 2005 inclusive.

The analysis was carried out by Sandra Edwards from the Oxford Cancer Intelligence Unit (OCIU) and Andy Pring from the South West Public Health Observatory, with the support of Ruth Jack and Henrik Møller at the Thames Cancer Registry.

8.2 Analysed data

The following chart shows an overview of data collected for oral and larynx cancer for cases with a date of diagnosis between January 2004 and September 2005:

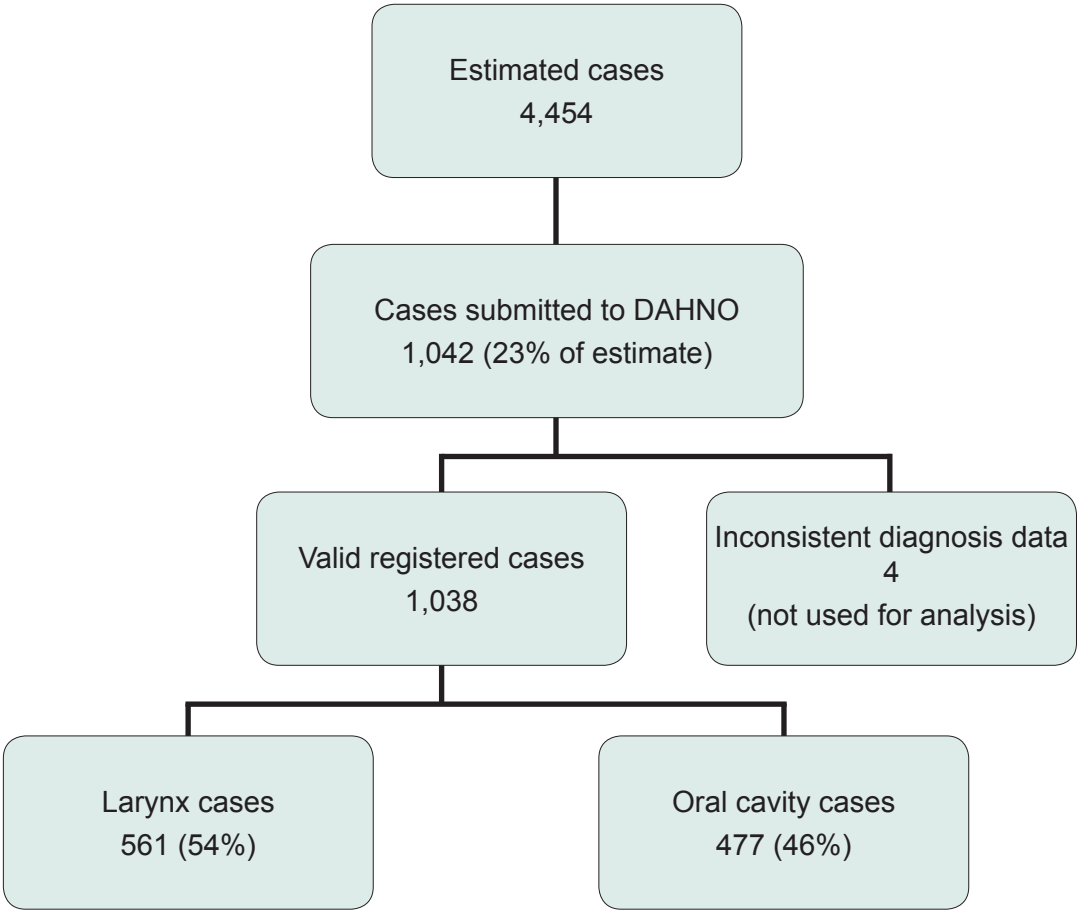


Fig 8.2a

It should be noted that organisations had the opportunity to join the audit at different points in the collection timeframe, with the last rollout meeting occurring in November 2004.

A considerable rise in case ascertainment is needed in future iterations of the audit to ensure a comprehensive reflection of current English head and neck cancer management.

8.3 Where head and neck cancer care happens

1,042 cases were presented for analysis. 1,038 cases were registered with a date of diagnosis between January 2004 and September 2005 into DAHNO. These comprised 561 (54%) laryngeal cancers and 477 (46%) oral cavity cancers. A breakdown of registrations by anatomic sub-site is included in figure 8.3.1a.

Four cases were excluded because of inconsistent diagnosis data.

8.3.1 Number of patients registered with new head and neck primaries of the larynx and oral cavity

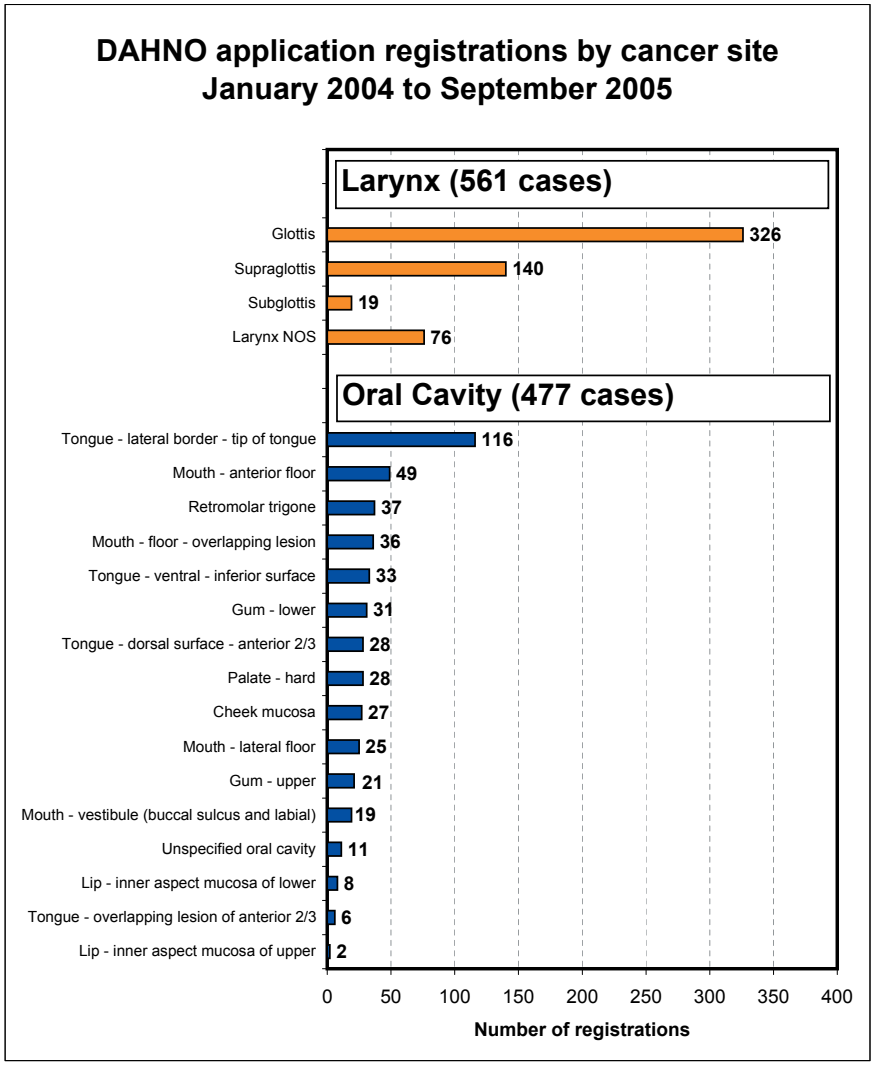


Figure 8.3.1a

In larynx, as expected, glottic cancers predominate, (58%), with 25% occurring in the supraglottis. 'Larynx NOS' (not otherwise specified) represents those cancers which involve

multiple sub-sites, and are also referred to as transglottic tumours, or it reflects failure to delineate the site of tumour origin. It is important that cancer site information is correctly entered to allow true comparison of sub-site outcomes and inter-regional differences. Four records have a missing specific cancer site recorded.

In oral cavity, anterior and lateral tongue are the most common cancer sites, (30%), with a more even distribution amongst the remaining sub-sites. Eleven records included in 'Unspecified oral cavity' have no specific cancer site code record.

8.3.2 Estimate of total number of patients with new head and neck primaries of the larynx and oral cavity in the index period

The following figure includes an estimate of the expected number of cases of larynx and oral cavity cancers per year in England. This data was used to estimate the maximum number of registrations the head and neck cancer audit might expect during the period covered by this report (21 months) in each cancer network.

The calculation of these estimates used two sources of information: the Office of National Statistics (ONS)[27] compilation of cancer registrations 2002 and the total of first attendances at hospital summarised by the cancer waiting time group[28] and cancer network (1999-2001) compiled from cancer registry data.

The cancer registry data is a good estimate of new patients, whilst the head and neck cancer waiting times group includes more cancer sites than oral cavity and larynx. The ONS data was used to estimate the proportion of the head and neck waiting time group that are larynx and oral cavity. Although cancer networks serve a geographically defined population, they may also see cross-border referrals.

- 1,038 patients, of a theoretical maximum total of 4,454 patients have been registered (23%) to the audit.
- Twenty-six out of 34 cancer networks have entered at least one patient onto the DAHNO application.
- The best performing cancer networks have managed to achieve high levels of registration. These have benefited from good organisation, shared learning and the investment by hospital trusts in data collection personnel.
- The multi-disciplinary team (MDT) meeting is a key focal point for data collection as the correct members of the team are assembled.
- The DAHNO application can receive data by either direct data entry or by the use of a csv upload facility. A number of organisations that collect data on in-house / third party systems have not taken the opportunity to contribute as yet. The DAHNO Helpdesk is available to help users contribute by this means, with both technical and practical advice.

DAHNO registrations January 2004 – September 2005 by cancer network			
Cancer network	DAHNO registrations	Estimate for 21 months	DAHNO registrations as % of estimate
South West London	145	138	105
Cancer Care Alliance of Teesside, South Durham and North Yorkshire	98	94	104
Merseyside and Cheshire	230	230	100
Leicestershire, Northants and Rutland	86	113	76
Mid Anglia	39	75	52
Norfolk and Waveney	29	63	46
Yorkshire	98	228	43
Pan Birmingham	72	175	41
Northern	89	227	39
Dorset	28	74	38
West Anglia	25	134	19
Arden	7	75	9
Greater Manchester and Cheshire	27	327	8
Derby / Burton	5	62	8
Mid Trent	11	149	7
Peninsula	11	167	7
North West Midlands	6	99	6
North London	7	122	6
South Essex	2	50	4
North Trent	5	152	3
Avon, Somerset and Wiltshire	5	157	3
Lancashire and South Cumbria	5	164	3
West London	4	134	3
Surrey, West Sussex and Hampshire	1	83	1
Thames Valley	2	178	1
Kent and Medway	1	151	1
Three Counties	0	92	0
Black Country	0	69	0
Central South Coast	0	194	0
Humber and Yorkshire Coast	0	92	0
Mount Vernon	0	82	0
North East London	0	96	0
South East London	0	120	0
Sussex	0	88	0
Total	**1038**	**4454**	**23**

Fig 8.3.2a

8.4 Who receives the care - demography, casemix and socio-economic status

8.4.1 Age and sex distributions of registrations

Larynx

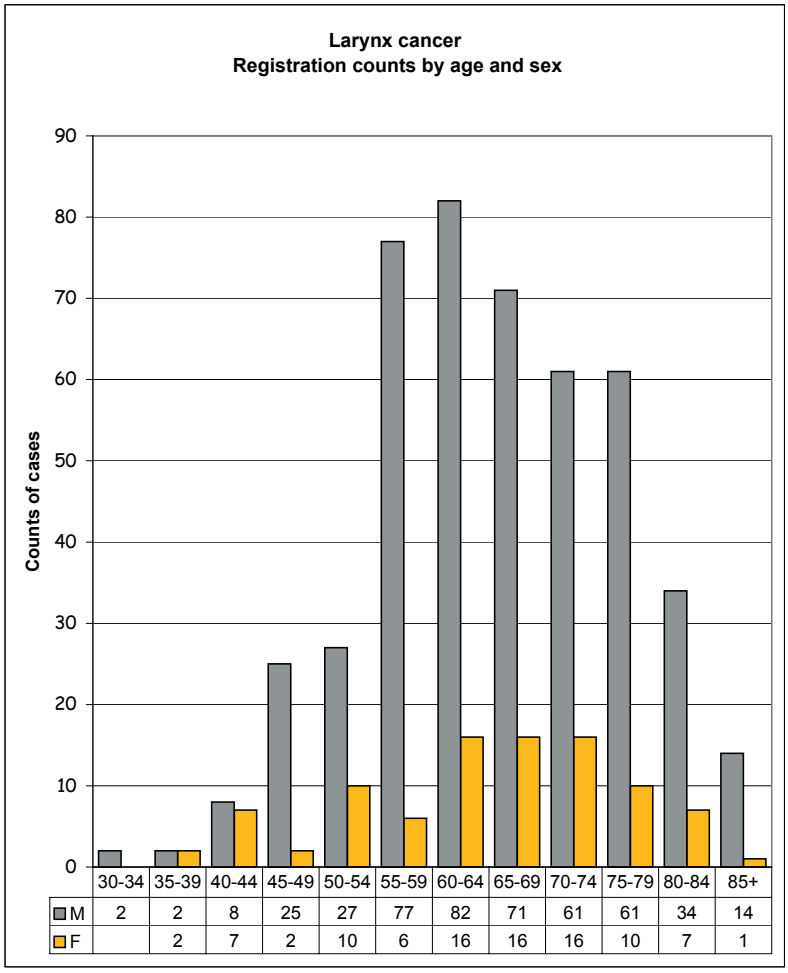
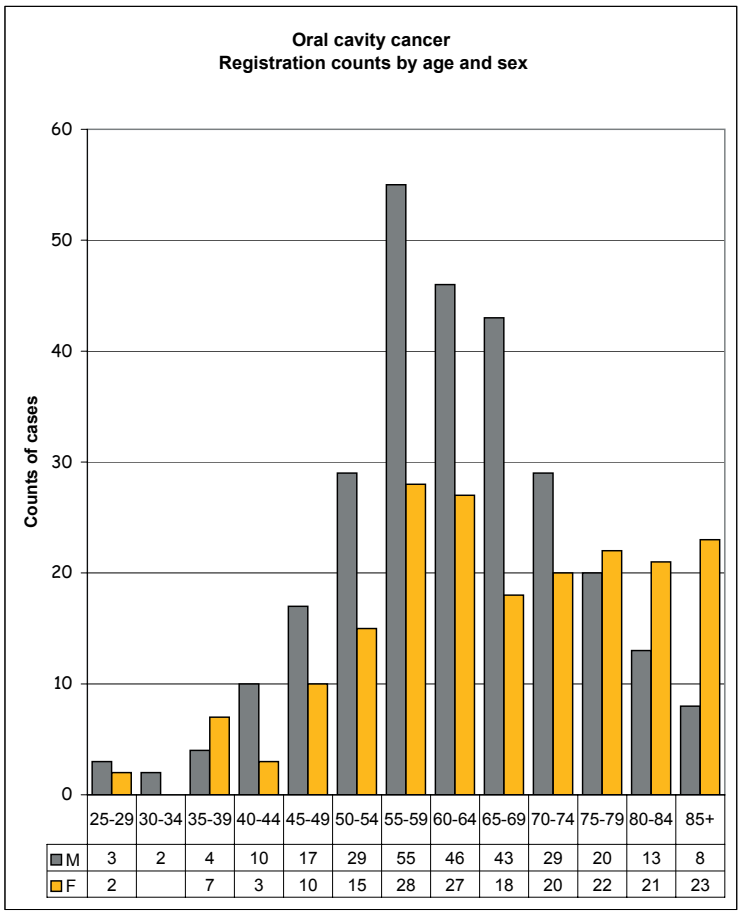


Figure 8.4.1a

Note: Three males have no recorded date of birth. One 70-74 year old has no recorded gender.

- 83% of cases were male.
- 9% of patients were aged under 50 years.
- The median age for both males and females was 65.
- 8% of male cases were aged under 50. 23% were aged over 75.
- 12% of female cases were aged under 50. 19% were aged over 75.

Oral cavity



	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
M	3	2	4	10	17	29	55	46	43	29	20	13	8
F	2		7	3	10	15	28	27	18	20	22	21	23

Figure 8.4.1b

Note: Three females have no recorded date of birth. For one person aged 50-54, no gender is recorded.

- 58% of cases were male.
- 12% of patients were aged under 50.
- The median age for males was 62, and 65 for females.
- 13% of male cases were under the age of 50. 15% were aged over 75.
- 11% of female cases were under the age of 50. 34% were aged over 75.
- The data suggests a single peak of registrations for males with a dual one for females.

A number of recent publications have demonstrated an increasing incidence of oral squamous cell carcinoma (particularly of the tongue) occurring in younger patients (under 40 years)[29]. Registrations do not appear to confirm the trend of a rising occurrence in young people. However, it needs to be borne in mind that this is an early stage of the audit[29].

8.4.2 Distribution of stage

8.4.2.1 Larynx

8.4.2.1.1 Stage at diagnosis

Percentages of 561 registered cases:

N Category	T Category						
	T1	T2	T3	T4	TX	Not recorded	Total
N0	20.5	17.3	8.4	3.9	0.2	4.8	**55.1**
N+	1.2	2.5	3.7	3.9	0.0	1.4	**12.8**
NX	0.7	0.4	0.2	0.4	0.0	0.0	**1.6**
Not recorded	0.2	0.5	0.2	0.0	0.0	29.6	**30.5**
Total	**22.6**	**20.7**	**12.5**	**8.2**	**0.2**	**35.8**	**100.0**

Figure 8.4.2.1.1a

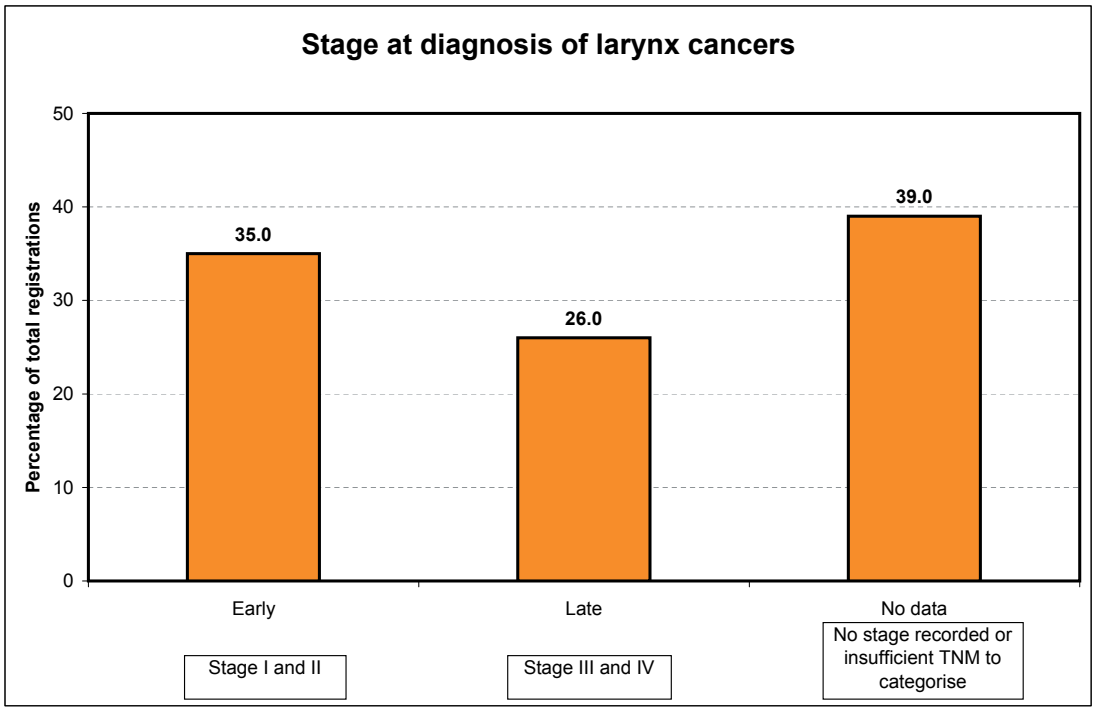


Figure 8.4.2.1.1b

- 61% of laryngeal cancers have stage at diagnosis recorded.
- 39% of laryngeal cancers have no staging recorded, which is disappointing.

Recording cancer site and accurate stage is a key medical responsibility, with best practice suggesting that this should be clearly documented and captured at the multi-disciplinary team (MDT) meeting. Staging remains a key influence on outcome. It is important that this

improves to achieve 100% of cases staged in any high quality database collection, to allow valid comparisons to be made.

The figure above suggests that early stage cancer predominates, but those with no data recorded could significantly influence this. The SWAHN 3 Audit (2002)[23] supports this finding in laryngeal cancer, again with early stage predominating. In oral cavity it will be noted later, with the same caveats, that late stage predominates.

8.4.2.1.2 Comparison of stage at diagnosis and post-surgery staging

Of the 88 patients recorded as undergoing surgery, information on stage at diagnosis, with post surgical staging (i.e. based on resective pathology), was available for T category in 48 patients and N category in 53 patients.

T		Diagnosis				
		T1	**T2**	**T3**	**T4**	**Total**
Post-surgery	**T1**	10				**10**
	T2		13			**13**
	T3			7		**7**
	T4		3	1	14	**18**
	Total	**10**	**16**	**8**	**14**	**48**

Figure 8.4.2.1.2a

- In T category, four patients were upstaged following surgery.

N		Diagnosis					
		N0	**N1**	**N2**	**N3**	**NX**	**Total**
Post-surgery	**N0**	32					**32**
	N1		8				**8**
	N2			11			**11**
	N3				1		**1**
	NX					1	**1**
	Total	**32**	**8**	**11**	**1**	**1**	**53**

Figure 8.4.2.1.2b

- No change in N category has occurred, which is a surprisingly high level of correlation. The sample size however is too small and incomplete at this stage to draw any definitive conclusions.

8.4.2.1.3 Summary of recorded stage certainty

Percentages of cases with recorded TNM staging (359 T stage recorded, 381 N stage recorded and 345 M stage recorded):

Stage category	Stage certainty				
	C1	C2	C3	C4	Not recorded
Cases with recorded T category	16.2	19.8	10.6	1.1	52.4
Cases with recorded N category	21.3	18.6	5.0	0.5	54.6
Cases with recorded M category	25.5	17.7	0.6	0.0	56.2

Figure 8.4.2.1.3a

- 52.4% had no T stage certainty factor recorded, 54.6% had no N stage certainty factor recorded and 56.2% had no M stage certainty factor recorded.

At key points in the patient pathway, staging is a defining parameter which allows for more interpretation of outcome, which facilitates grouping a description of disease extent in a uniform manner, to allow valid comparison.

Certainty factor	
C1	Evidence from standard diagnostic means *(e.g. inspection, palpation, and standard radiography, intraluminal endoscopy for tumours of certain organs)*
C2	Evidence obtained by special diagnostic means *(e.g. radiographic imaging in special projections, tomography, computerised tomography (CT), ultrasonography, lymphography, angiography, scintigraphy, magnetic resonance imaging (MRI), endoscopy, biopsy and cytology)*
C3	Evidence from surgical exploration, including biopsy and cytology
C4	Evidence of the extent of disease following definitive surgery and pathological examination of the resected specimen
C5	Evidence from autopsy

Figure 8.4.2.1.3b

Stage certainty is a relatively new concept to clinicians and links to the category (TNM) recorded, the means by which this was established, and the degree of confidence associated with the diagnosis[9].

- One-third of larynx cases had certainty factor completed, which is a good start, but highlights that awareness and training on completion of certainty factor needs to be increased. In particular, it would be expected that the numbers with C4 should be greater based on the number of resective procedures performed.

8.4.2.2 Oral cavity

8.4.2.2.1 Diagnosis stage

Percentages of 477 registered cases:

N Category	T Category						
	T1	T2	T3	T4	TX	Not recorded	Total
N0	17.6	15.7	3.6	11.7	0.2	0.7	**49.5**
N+	4.0	8.0	1.9	8.0	0.0	1.0	**22.9**
NX	0.2	0.6	0.0	0.0	0.2	0.0	**1.0**
Not recorded	0.2	0.4	0.0	0.4	0.0	25.6	**26.6**
Total	**22.0**	**24.7**	**5.5**	**20.1**	**0.4**	**27.3**	**100.0**

Figure 8.4.2.2.1a

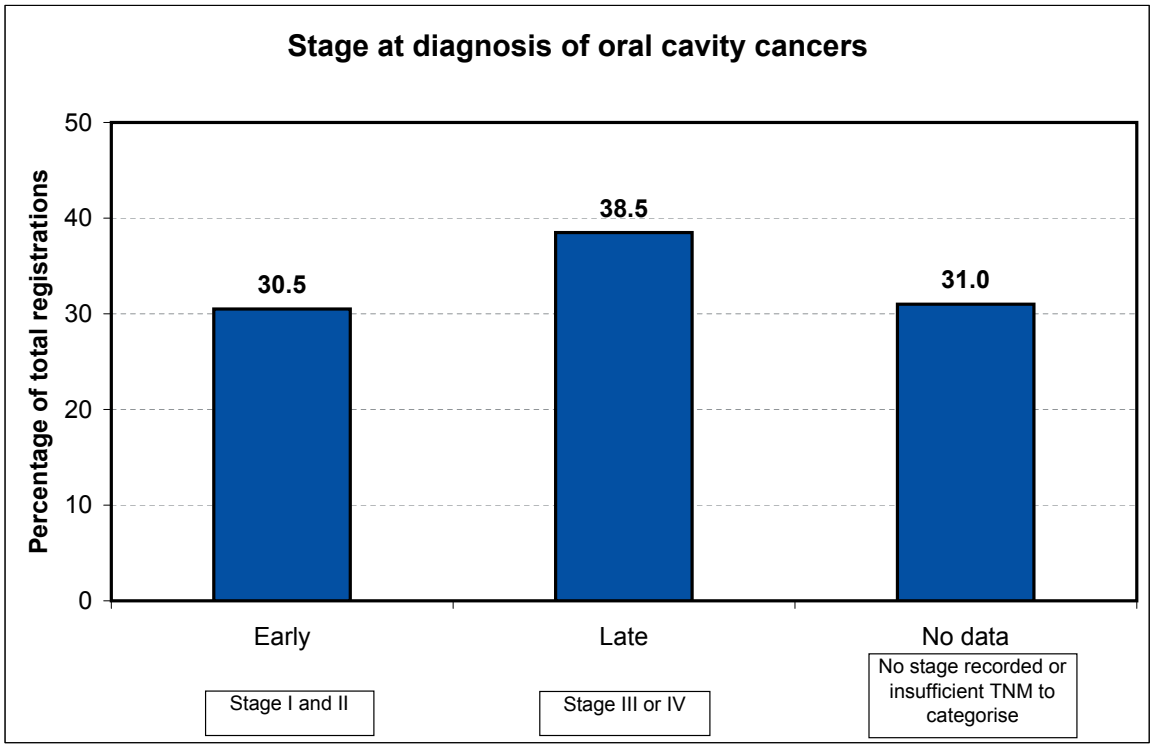


Figure 8.4.2.2.1b

- 69.5% of oral cavity cancers have stage at diagnosis recorded.
- 31% of oral cavity cancers have no staging recorded which is disappointing.

Recording cancer site and accurate stage is a key medical responsibility, with best practice suggesting that this should be clearly documented and captured at the MDT. Staging remains a key influence on outcome. It is important that this improves to achieve 100% of cases staged in any high quality database collection, to allow valid comparisons to be made.

The figure above suggests that late stage cancer predominates, but those with no data could significantly influence this. In laryngeal cancer it should be noted, with the same caveats, that early stage predominates.

8.4.2.2.2 Comparison of stage at diagnosis and post-surgery staging

Of the 211 patients recorded as undergoing surgery, information on stage at diagnosis, with post surgical staging (i.e. based on resective pathology), was available for T category in 152 patients and N category in 154 patients.

T		Diagnosis				
		T1	T2	T3	T4	Total
Post-surgery	T1	60	3		1	64
	T2	3	43	1	1	48
	T3		3	7	1	11
	T4		3		26	29
	Total	63	52	8	29	152

Figure 8.4.2.2.2a

- In T category, seven patients were downstaged and nine cases were upstaged following surgery (11% change in stage).

N		Diagnosis				
		N0	N1	N2	NX	Total
Post-surgery	N0	101	3	4		108
	N1	3	21	2		26
	N2	1	5	9		15
	NX	3		1	1	5
	Total	108	29	16	1	154

Figure 8.4.2.2.2b

- In N category, nine patients were downstaged and 13 cases were upstaged following surgery (12% change in stage).

In general, it would be expected that a greater variation would occur in N category.

8.4.2.2.3 Summary of recorded stage certainty

Percentages of cases with recorded TNM staging (345 T stage recorded, 345 N stage recorded, and 307 M stage recorded):

Stage category	Stage certainty				
	C1	C2	C3	C4	Not recorded
Cases with recorded T category	18.8	19.1	12.8	5.2	44.1
Cases with recorded N category	25.5	23.5	4.1	3.8	43.2
Cases with recorded M category	36.2	14.7	0.3	2.6	46.3

Figure 8.4.2.2.3a

- 44.1% had no T stage recorded, 43.2% had no N stage recorded and 46.3% had no M stage recorded.

At key points in the patient pathway, staging is a defining parameter that allows for more interpretation of outcome, which facilitates grouping a description of disease extent in a uniform manor, to allow valid comparison.

Certainty factor	
C1	Evidence from standard diagnostic means *(e.g. inspection, palpation, and standard radiography, intraluminal endoscopy for tumours of certain organs)*
C2	Evidence obtained by special diagnostic means *(e.g. radiographic imaging in special projections, tomography, computerised tomography(CT), ultrasonography, lymphography, angiography, scintigraphy, magnetic resonance imaging (MRI), endoscopy, biopsy and cytology)*
C3	Evidence from surgical exploration, including biopsy and cytology
C4	Evidence of the extent of disease following definitive surgery and pathological examination of the resected specimen
C5	Evidence from autopsy

Figure 8.4.2.2.3b

Stage certainty is a relatively new concept to clinicians and links to the category (TNM) recorded, the means by which this was established and the degree of confidence associated with the diagnosis.

- One-third of oral cavity cases had certainty factor completed, which is a good start, but highlights that awareness and training on completion of certainty factor needs to be increased. In particular it would be expected that the numbers with a certainty factor of C4 should be greater based on the number of resective procedures performed.

8.4.3 Distribution of performance status at point of treatment decision

Larynx

Performance status	% of 167 recorded values
0. Able to carry out all normal activity without restriction	40.7
1. Restricted in physically strenuous activity	14.4
2. Able to walk and capable of all self care but unable to carry out any work	5.4
3. Capable of only limited self care	0.6
4. Completely disabled	0.6
5. Not recorded	38.3
Total	**100.0**

Figure 8.4.3a

Oral cavity

Performance status	% of 167 recorded values
0. Able to carry out all normal activity without restriction	43.7
1. Restricted in physically strenuous activity	15.8
2. Able to walk and capable of all self care but unable to carry out any work	7.4
3. Capable of only limited self care	3.7
4. Completely disabled	0.5
5. Not recorded	28.9
Total	**100.0**

Figure 8.4.3b

- 880 patients had at least one careplan. (A careplan represents the point in the patient pathway where a plan of treatment is proposed and thus an appropriate point to assess and record a patient's fitness).

- 357 patients had performance status recorded, which is 34% of the total registrations. This equates to 40% of patients with a recorded careplan.

To facilitate risk adjustment further, training on performance status and completeness is required. The figures so far suggest that the majority of patients have a normal performance status and there appears to be equivalence between the oral cavity and laryngeal groups.

8.4.4 Presence or absence of significant comorbidity at index point of diagnosis (ACE-27)

- 880 patients had at least one careplan.
- 190 patients had comorbidity index recorded. This is 22% of patients with a recorded careplan, which is 18% of total registrations.

8.4.4.1 Summary of recorded comorbidity

Grade	% of recorded values (190 records)
Grade 0 - No comorbidity	31.6
Grade 1 - Mild decompensation	19.5
Grade 2 - Moderate decompensation	22.1
Grade 3 - Severe decompensation	26.8

Figure 8.4.4.1a

Comorbidity is a new concept for clinical teams. It has been shown to have an important impact in assessing risk and to be an important predictor of outcome. Further effort will be put into training workshops to encourage completeness.

- The figures so far show similar results for no comorbidity but a greater frequency of moderate and severe decompensation compared to a previous UK population of larynx only cancer patients studied[30].
- The figures for comorbidity suggest that 50% of the total population (larynx and oral cavity) patients had moderate or severe decompensation. This does not appear to tally with the normal performance status in the previous output (8.4.3). Additional work is required to define this further.

8.4.5 Distribution of diagnosis, treatment and outcome by socio-economic super-group, derived from the postcode

The Index of Multiple Deprivation 2004 (IMD 2004) was used as a measure of socio-economic deprivation[30].

This index is a combination of sub-indices:

- Income
- Employment

- Heath deprivation and disability
- Education, skills and training deprivation
- Barriers to housing and services
- Living environment deprivation
- Crime.

The index has been calculated for each of 32,482 areas of the country and categorical quintiles of deprivation are derived from the rank of this score. A patient's recorded postcode assigns that individual to one particular area and hence the associated deprivation quintile.

The lower the index score, the greater the level of deprivation, thus the first quintile represents those who are most deprived.

Fifty-three registrations did not have a valid postcode and, therefore, a deprivation score could not be calculated.

8.4.5.1 Summary of registrations by deprivation

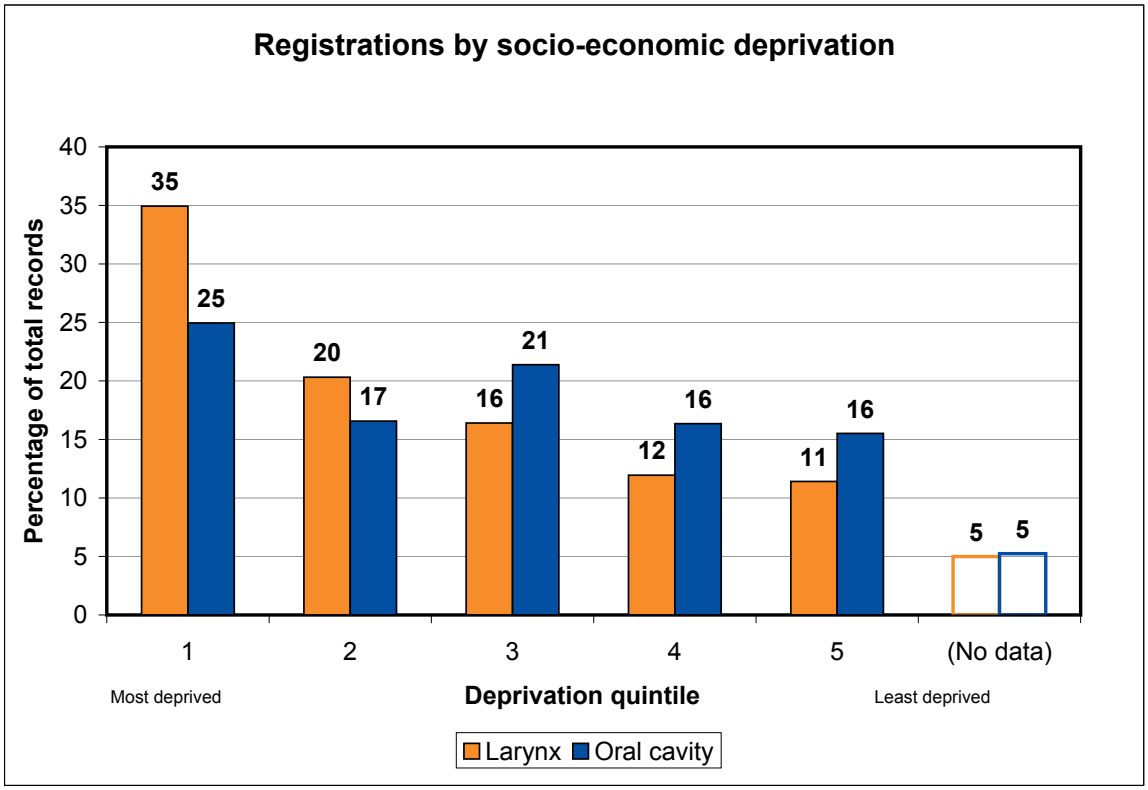


Figure 8.4.5.1a

- Over half of patients with laryngeal cancer reside in areas of relative deprivation (quintiles one and two). Oral cavity registrations are more evenly distributed across the deprivation quintiles.

8.4.5.2 Deprivation and stage

Early – 1-2, Late – 3-4

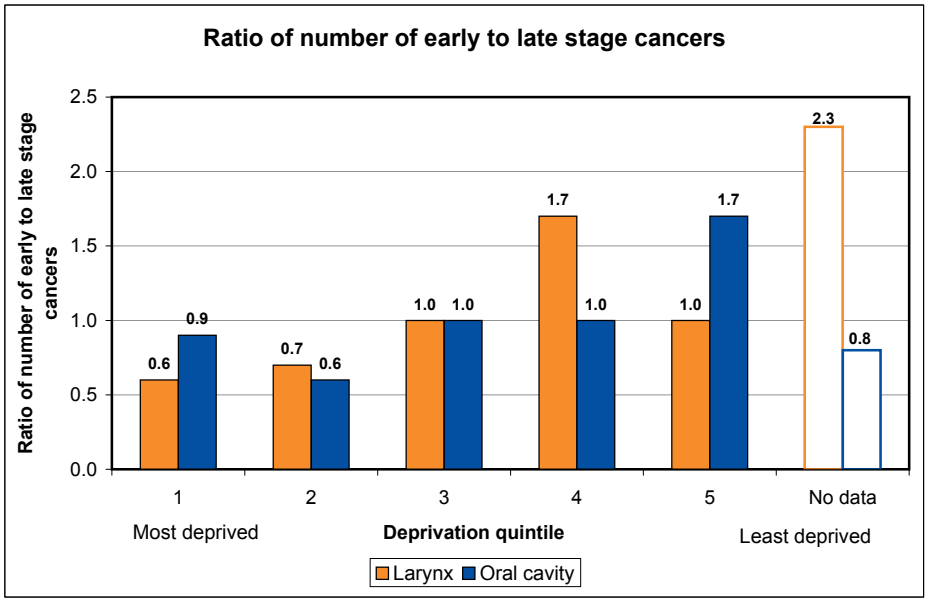


Figure 8.4.5.2a

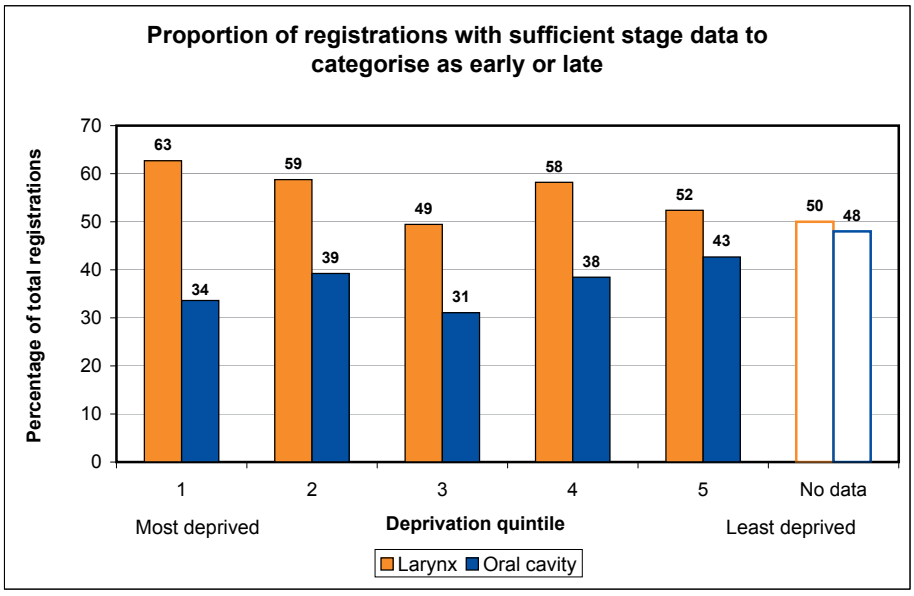


Figure 8.4.5.2b

Note: Early stage cancer refers to overall stage I and II, and late stage cancer to overall stage III and IV.

Limited conclusions can be drawn from this chart regarding any relationship between stage at diagnosis and deprivation. There is a weak indication that at diagnosis late stage cancer is more likely in the most deprived, while amongst the least deprived early stage cancer is more common. However, any interpretation is hampered by the lack of recorded staging; approximately half of all registrations have sufficient data to be categorised as early or late. Better data submissions in the future will enable more in depth analysis. This is an area of significant interest and will be examined more closely in future reports.

8.4.5.3 Deprivation and interval from referral to treatment

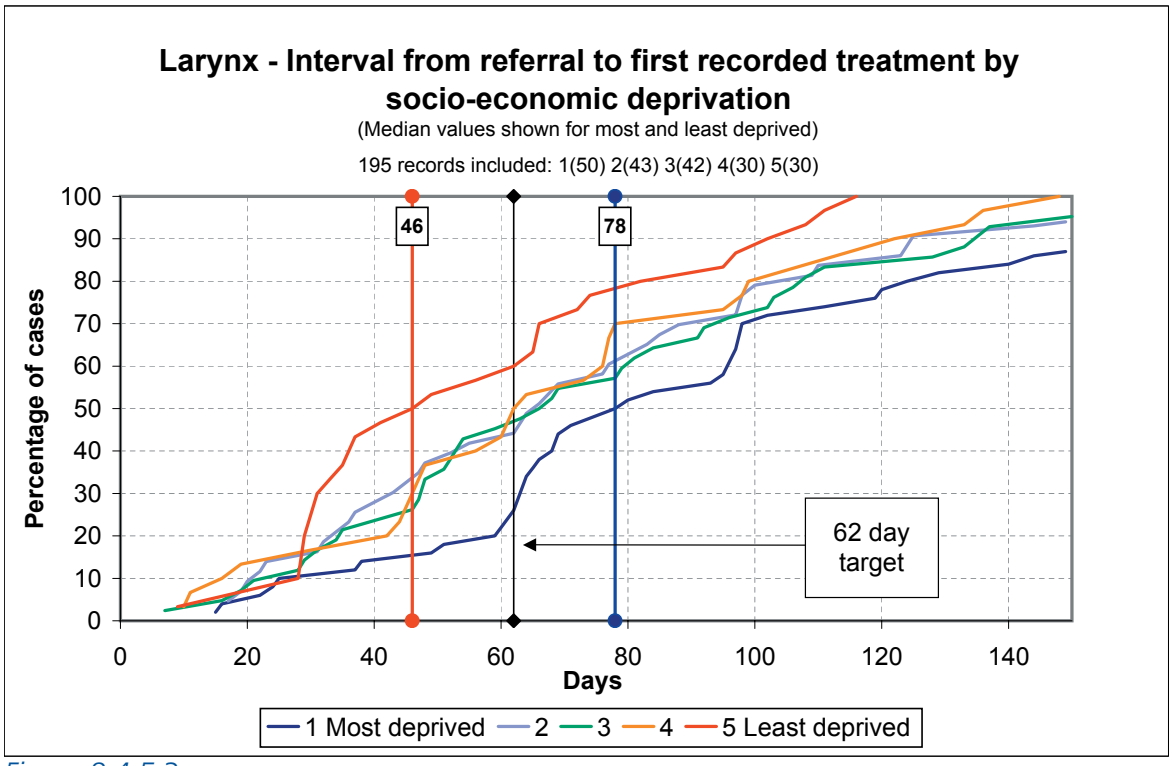


Figure 8.4.5.3a

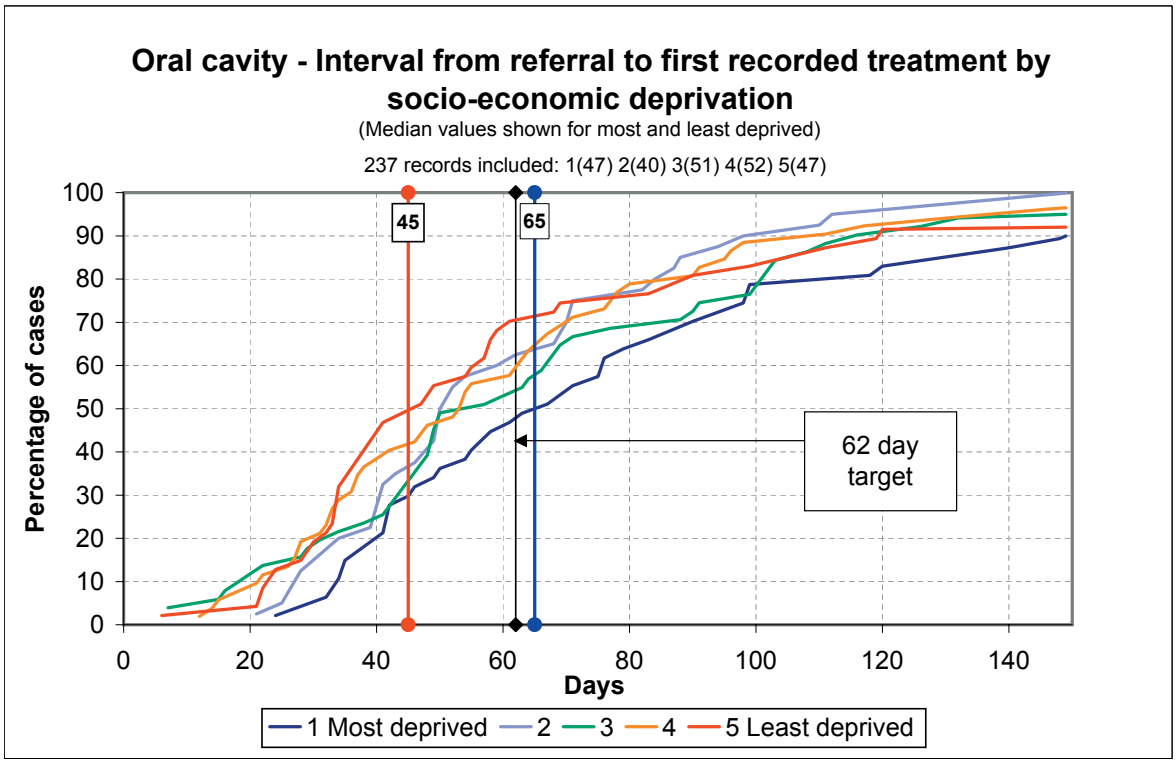


Figure 8.4.5.3b

Note: The 62-day target applies from the 1 January 2006. This expectation does not relate to the data extraction period of date of diagnosis used for this analysis.

- In both larynx and oral cavity, the median interval from referral to first treatment was 45 days in the least deprived, whilst in the most deprived this is 78 and 65 days respectively.

8.4.5.4 Interval to first treatment by stage

A possible inference from the suggestion that, a diagnosis with late stage disease may be more common amongst deprived populations and the interval from referral to treatment is longer for more deprived populations, is: 'Are those with more advanced disease waiting longer for treatment?' Given the poor completeness of staging data, this is difficult to assess with confidence. However an analysis of those patients for which the DAHNO application has both a referral date and a treatment date split by early / late stage yields the following graphs:

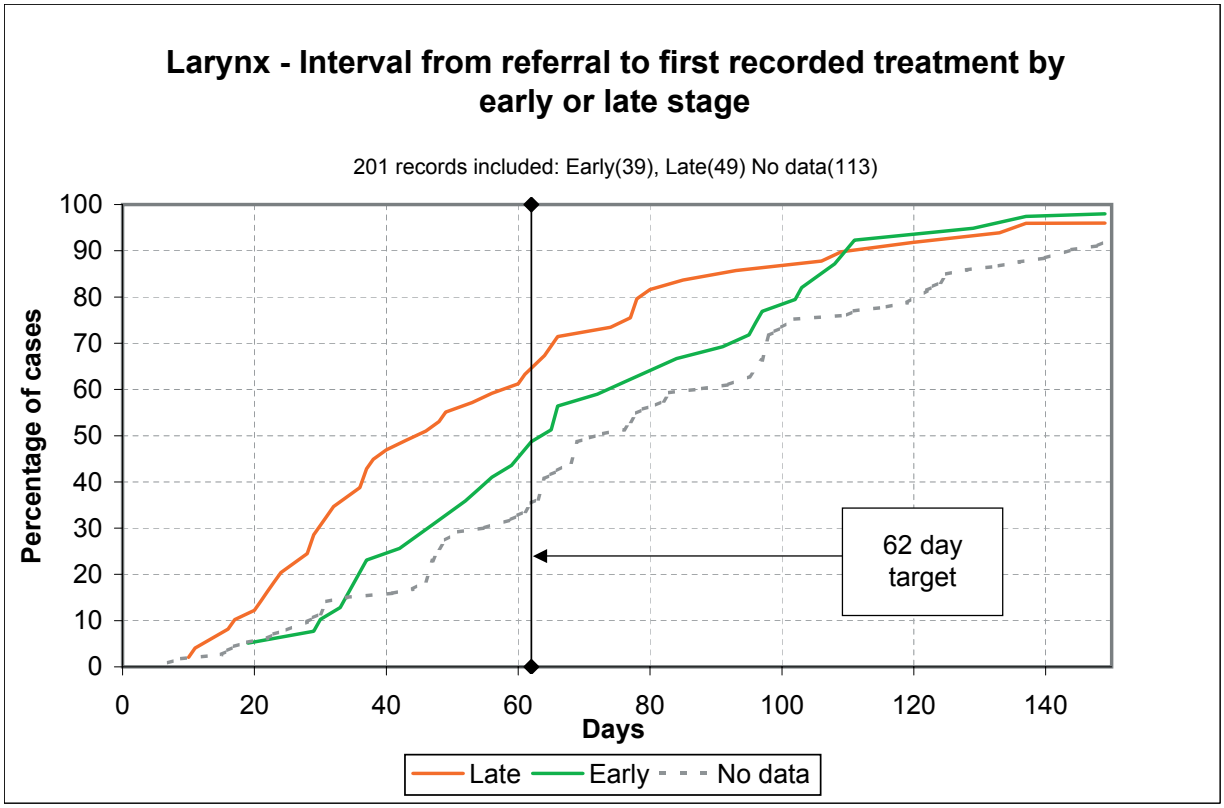


Figure 8.4.5.4a

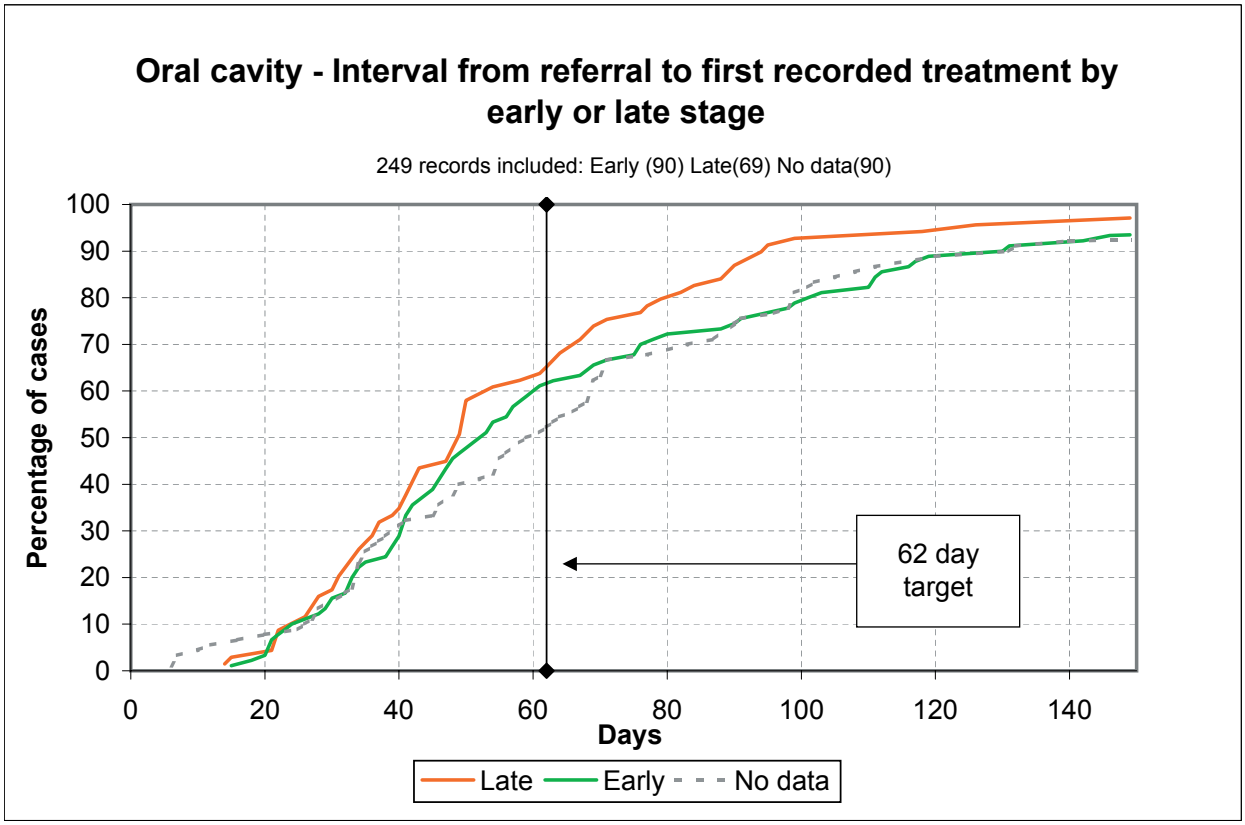


Figure 8.4.5.4b

- There is no indication that patients with late stage disease are receiving treatment later than patients with early stage disease.

8.5 The patient journey - diagnostic and staging process, waiting intervals

8.5.1 Source of referral to specialist team

8.5.1.1 Larynx

Primary referral source	2WW from GP or dentist	Other	Not recorded	Total
GP	171	105	9	**285**
Emergency admission / A&E		21	1	**22**
Consultant	14	96	3	**113**
Self / other		34	1	**35**
Not known / not recorded	1	4	101	**106**
Total	**186**	**260**	**115**	**561**

Figure 8.5.1.1a

- There is a ratio of 1.7:1 in referral via the two-week wait urgent pathway to other priorities, in referrals from general practitioners in those with diagnosed cancer. However, the audit has not sampled the total number of referrals from which these derived.

- Under the two-week wait referral category, 14 referrals are recorded as from another consultant. The two-week wait rule only applies to referrals from primary care, and this appears to reflect some difficulty in categorisation by users.

8.5.1.2 Oral cavity

Primary referral source	2 WW from GP or dentist	Other	Not recorded	Total
GP	132	55	2	**189**
GDP / CDS	27	57	3	**87**
Emergency admission / A&E		6	2	**8**
Consultant	6	83	3	**92**
Self / other	1	27	1	**29**
Not known / not recorded	1	5	66	**72**
Total	**167**	**233**	**77**	**477**

Figure 8.5.1.1b

- There is a ratio of 2.5:1 in referral via the two-week wait urgent pathway to other priorities, in referrals from general medical practitioners in those with diagnosed cancer, and a ratio of 1:2 for those referred under the two-week wait from general dental practitioners (GDP) / Community Dental Services (CDS). General dental practitioners have not been involved in the urgent cancer referral process since its launch. Targeted publications and their future involvement in the two-week wait referral pathway may improve this. The audit, however, has not sampled the total number of referrals from which these derived.

- Under the two-week wait referral category, six referrals are recorded as from another consultant and one as self referred. The two-week wait rule only applies to referrals from primary care, and this appears to reflect some difficulty in categorisation by users.

8.5.2 Summary as percentage of cases with both 'primary referral priority' and 'primary referral source' completed

8.5.2.1 Larynx

Percentages of 441 cases:

Primary referral source	2WW from GP	Other	Total
GP	38.8	23.8	**62.6**
Emergency admission / A&E		4.8	**4.8**
Consultant	3.2	21.7	**24.9**
Self / other		7.7	**7.7**
Total	**42.0**	**58.0**	**100.0**

Figure 8.5.2.1a

- 62.6% of those diagnosed with laryngeal cancer are referred by their general practitioner, whilst of the remaining 40%, 25% are referred from another consultant.

8.5.2.2 Oral Cavity

Percentages of 394 cases:

Primary referral source	2 WW from GP or dentist	Other	Total
GP	33.5	14.0	**47.5**
GDP / CDS	6.9	14.5	**21.3**
Emergency admission / A&E		1.5	**1.5**
Consultant	1.5	21.1	**22.6**
Self / other	0.3	6.9	**7.1**
Total	**42.1**	**57.9**	**100.0**

Figure 8.5.2.2a

- 47.5% of those diagnosed with oral cavity cancer are referred by their general practitioner, while of the remaining 50%, 22% are referred from another consultant and 21% from a general dental practitioner or the Community Dental Service. This demonstrates the importance of general dental services in screening for oral cavity cancer.

8.5.3 Interval from first symptom to referral to specialist team

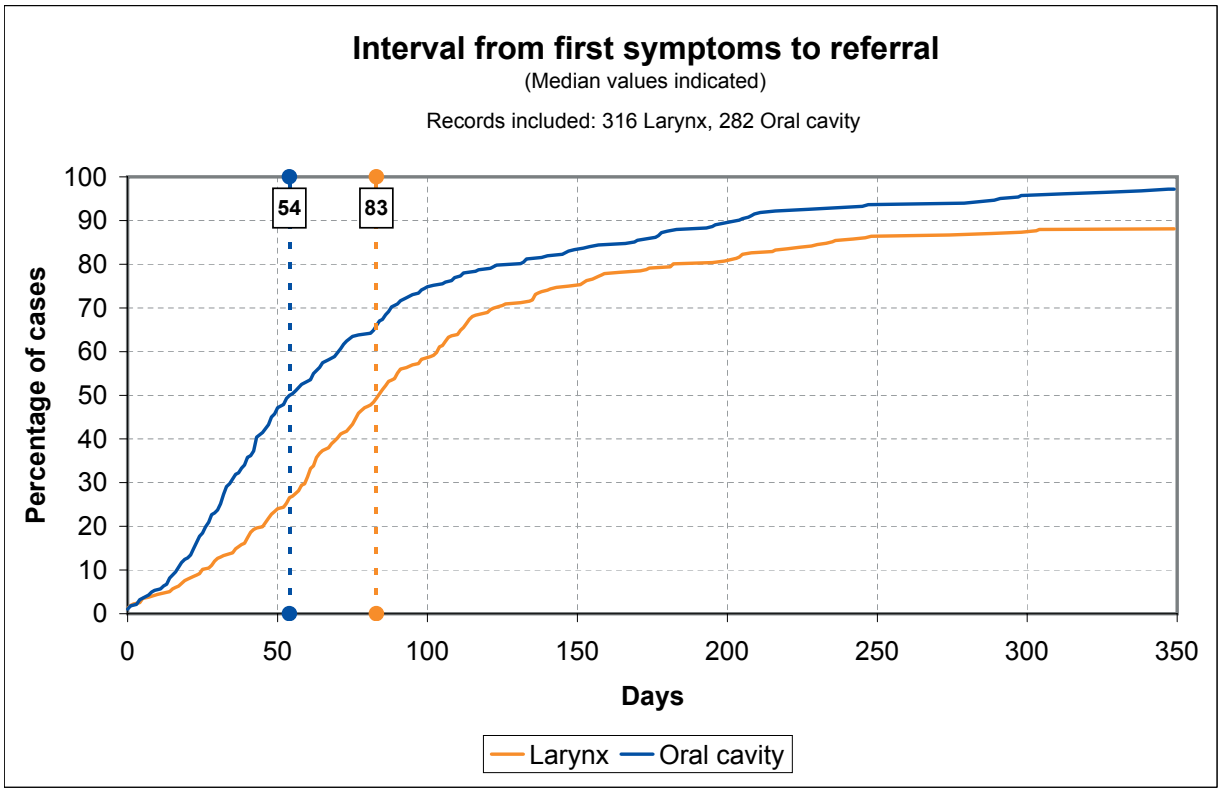


Figure 8.5.3a

Patient recall of the onset of their first symptom to their point of referral is a crude indicator of patient awareness.

- The figures presented suggest earlier presentation of oral cavity cancer (median interval 54 days) compared to laryngeal cancer (median interval 83 days). This may be because within the oral cavity, cancers are more visible.

The significance of delay in outcome and stage at presentation remains controversial[32-38]. Increasing patient and practitioner awareness of suspicious symptoms should yield an early diagnosis, particularly in larynx cancer.

Practitioners should be encouraged to familiarise themselves with and utilise national referral guidelines. National referral guidelines (Referral Guidelines for Suspected Cancers) can be found at **www.dh.gov.uk/assetRoot/04/01/44/21/04014421.pdf**

8.5.4 Interval from referral to first appointment

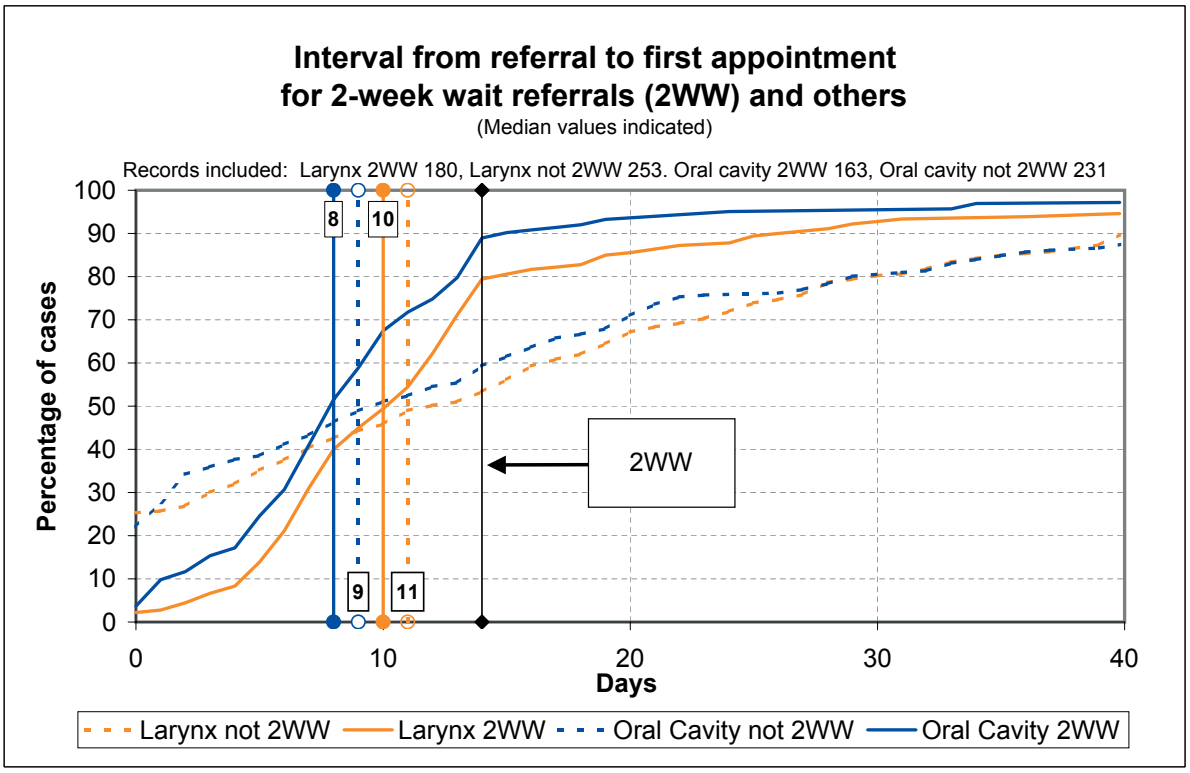


Figure 8.5.4a

- The figure shows that for non two-week wait referrals, nearly one-quarter have an interval from referral to first appointment of 0 days. This reflects self-referrals, referrals to an Accident and and Emergency Service and those seen on the day of phone or fax request.

The two-week wait rule for referral to first appointment was introduced in December 2000[39]. This is designed to speed up the patient's entry into the cancer care pathway.

- The median for both larynx and oral cavity two-week wait and other referrals is comfortably within the standard, showing that patients with suspicious symptoms independent of route of referral are seen promptly. However 20% of other referrals in the sample are waiting over one month for their first appointment.

- With the implementation of National referral guidelines, (Guidance on Cancer Services - Improving Outcomes in Head and Neck Cancers[40] and Referral Guidelines for Suspected Cancers[41]), it would be expected that an ever increasing proportion of patients will be referred via the two-week wait pathway.

8.5.5 Interval from referral to diagnosis

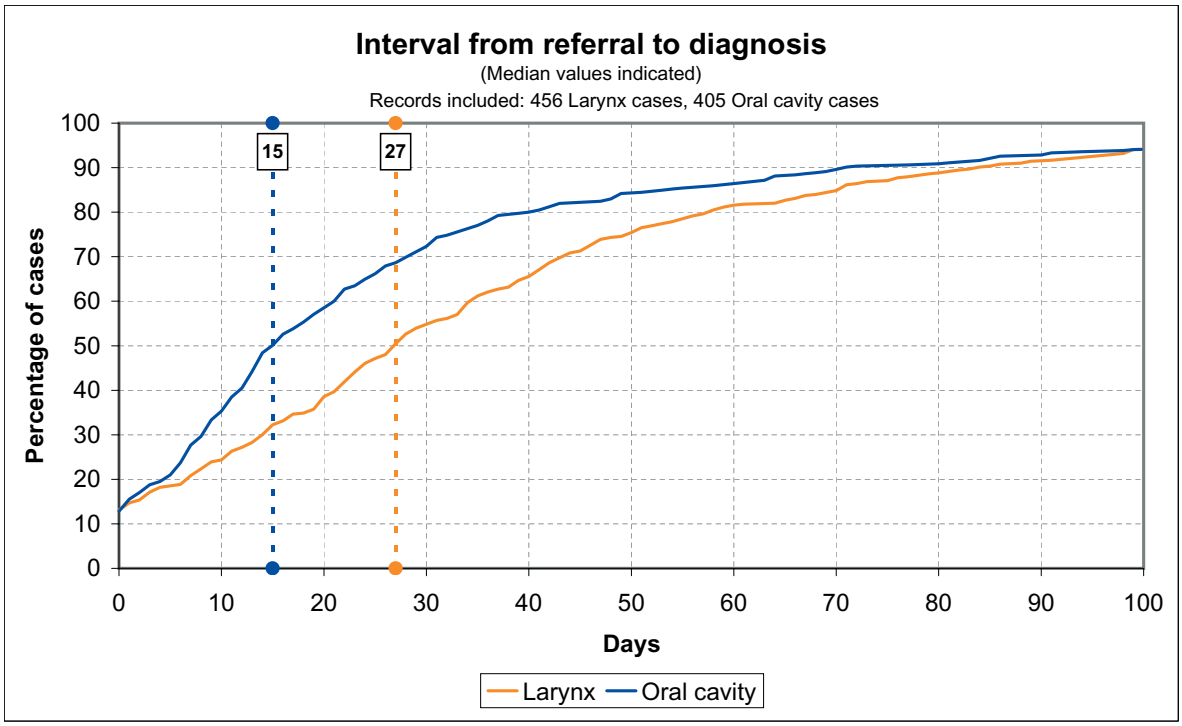


Figure 8.5.5a

The apparent more rapid diagnosis of oral cavity cancers may be explained by the fact that many of these diagnoses can be achieved via local anaesthetic out-patient biopsy, whereas for laryngeal cancer the requirement for general anaesthesia may induce additional delays.

In both larynx and oral cavity cancer, patients may present initially with precancerous lesions that are carefully followed up over extended periods. This can, therefore, mean that their ultimate diagnosis of cancer from referral may not occur until a significant time has elapsed. This is likely to explain why the graph shows that only 90% of patients reach a diagnosis by 100 days and then plateaux.

8.5.6 The multi-disciplinary team (MDT) and its functions

The percentage discussed at the multi-disciplinary team (MDT) meeting is as follows:

Discussed	Larynx	Oral cavity	All
Yes	60.4	75.7	67.5
No	20.9	9.3	15.5
Not recorded	18.7	14.9	17.0

Figure 8.5.6a

Note: Although this table reflects the number of patients discussed at MDT and this report makes reference to the MDT meeting, we refer to the standard definition of MDT from Improving Outcomes Guidance (IOG). The data collected for the head and neck cancer audit does not indicate the understanding of what constitutes MDT.

- Overall two-thirds of patients were confirmed as having been discussed at an MDT meeting. The expected standard (proposed in the SWAHN audit 1997-1999)[21] suggested this should reach 100%, but there may always be a rare exception.
- It is a standard in the Improving Outcomes Guidance that all patients are discussed in an MDT meeting.
- These results may reflect a non-ideal pathway with treatment decisions being made outside of MDTs.
- The MDT meeting is a key point of registration of a cancer diagnosis.

8.5.7 Interval from diagnosis to decision to treat

A number of key events occur in the cancer care pathway, and the following three graphs reflect time intervals along that path.

The point of diagnosis reflects the date upon which a biopsy was taken rather than the date histology was reported. The date of the multi-disciplinary team (MDT) meeting where care options were discussed is reflected in the date MDT management was planned. The careplan agreed date is the date upon which the treating clinician and patient agree that care pathway. The date of 'primary care notification' is the date that communication was sent to the primary care practitioner.

8.5.7.1 Interval from diagnosis to MDT ('triage' date)

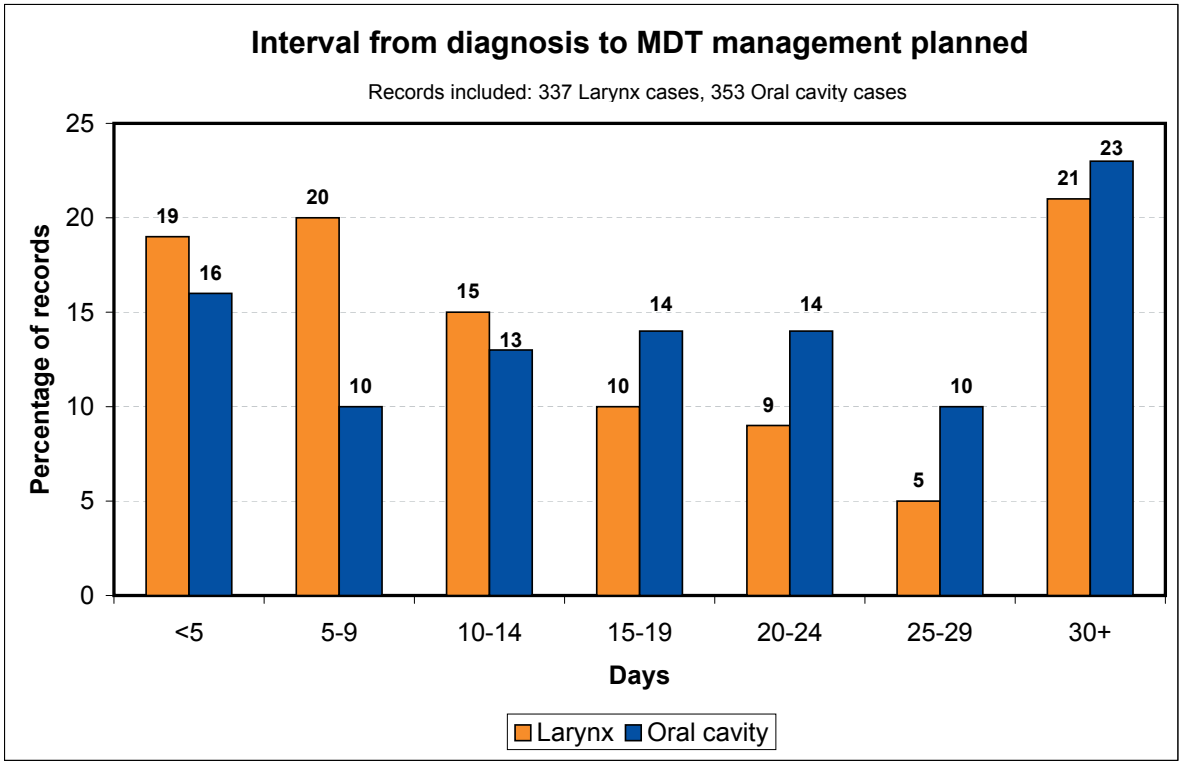


Figure 8.5.7.1a

- The median interval from diagnosis to MDT for larynx patients is 13 days and for oral cavity patients it is 19 days.

The interval from diagnosis to MDT reflects transfer of the biopsy to the laboratory, processing of the specimen and its reporting, receipt of the report and booking to the next MDT. An interim step can be a return to out patients when an unexpected diagnosis arises.

- Just under 80% of patients with both oral cavity and laryngeal cancer have their MDT management planned in less than 30 days from the biopsy being taken.

- Within the 62-day target for the two-week wait referral to treatment (effective from 1 January 2006)[15] referral to first treatment interval will need to be reduced further.

8.5.7.2 Interval from diagnosis to date careplan agreed

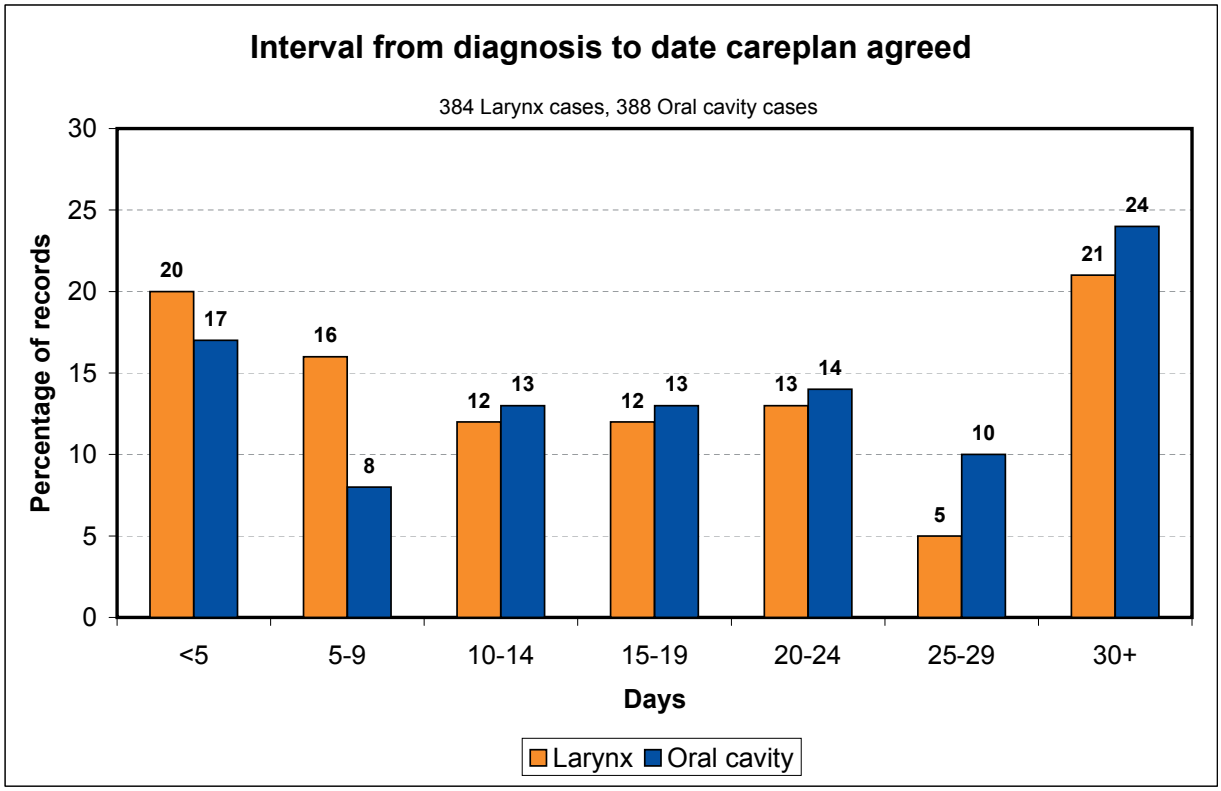


Figure 8.5.7.2a

- The median interval from diagnosis to date careplan agreed for larynx patients is 15 days and for oral cavity patients it is 19 days.

- The difference in totals in the above graph, compared to the former graph, indicates that some patients are agreeing a careplan without attending an MDT.

It is an accepted standard that all patients are discussed in an MDT[40]. This may reflect a non-ideal pathway or may be a reflection of poor data quality.

- This chart appears to demonstrate that the majority of careplans are agreed within a short interval of the MDT meeting.

8.5.7.3 Interval from date careplan agreed to sending communication to primary care

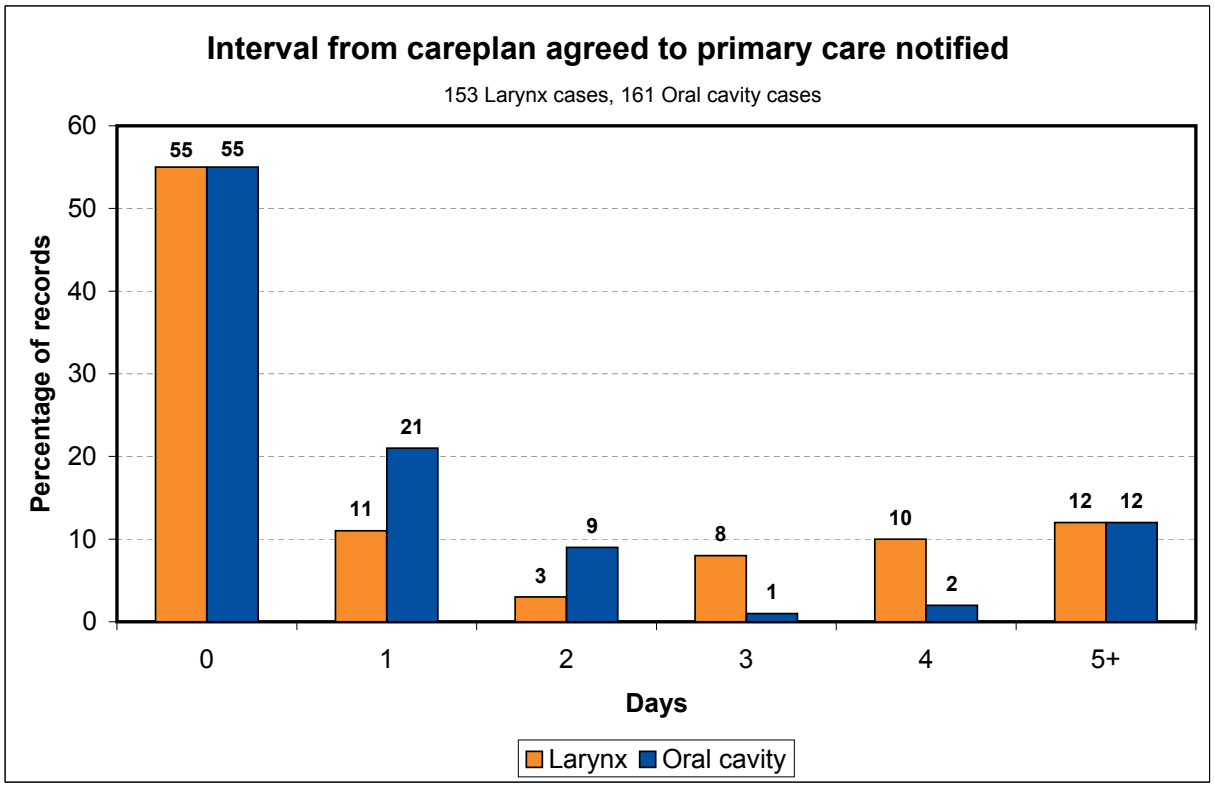


Figure 8.5.7.3a

- Where this information is recorded, in over 50% of cases, primary care notification occurred on the same day. However, only one-third of cases had this information recorded. Best practice would be supported by confirmation that this standard is being achieved for all patients.

8.5.8 Percentage with histological confirmation prior to cancer careplan

- 802 patients can be associated with a diagnostic pathology date, 710 of these patients have a careplan date (348 larynx, 362 oral cavity).

- Of these, 300 larynx (86%) and 321 oral cavity (89%) patients have histological confirmation before the careplan.

In head and neck cancer, it would be expected that all patients would have histological confirmation of a tumour prior to the agreement of a careplan, and the results seem likely to reflect poor data quality.

There is a significant risk in proceeding to a cancer careplan without written histological confirmation of diagnosis, as rarely other conditions such as tuberculosis can mimic cancer.

8.5.9 Percentage with staging information recorded at time of cancer careplan

The percentage with staging information recorded at time of cancer careplan reflects the percentage of patients with a careplan (indicated by record of 'management planned date' or non-blank 'careplan agreed date') with some recorded T, N or M diagnostic staging.

Count	Larynx	Oral cavity	Total
Yes	280	307	**587**
No	115	83	**198**
Total	**395**	**390**	**785**

Figure 8.5.9a

%	Larynx	Oral cavity	Total
Yes	71	79	**75**
No	29	21	**25**
Total	**100**	**100**	**100**

Figure 8.5.9b

- Overall, of those patients with a recorded careplan, 75% had recorded staging information. Whilst this figure is encouraging and similar to that found in the SWAHN 1 audit (1997-1999)[21] we need to work towards a higher figure for future audits.

Staging of tumours is a critical part of the treatment pathway as well as being a key determinant of outcome.

All MDTs should be strongly encouraged to complete and validate staging information and validate outcome.

8.5.10 Percentage having chest imaging by chest x-ray (CXR) or chest computerised tomography (CT) prior to cancer careplan

- Imaging data is recorded for 58% of patients (603 of 1,038).

This output was intended to reflect best practice where due to the recognised incidence of second primary lung cancers[42], chest imaging should occur prior to a cancer careplan in all patients.

- Where both imaging and careplan data is recorded, 83% of larynx cases (125 of 150) and 72% of oral cavity cases (84 of 116) have chest imaging by x-ray or CT prior to careplan.

Whilst the level of completeness superficially appears poor for this item, it needs to be recognised that a design fault in the early version of the DAHNO application database did not allow correct recording of this information, and therefore results need to be interpreted with caution. This error has now been corrected.

8.5.11 Interval from imaging request to date imaging performed (CT / MRI) contributory to pre-treatment staging complying with the Royal College of Radiologists' guidelines

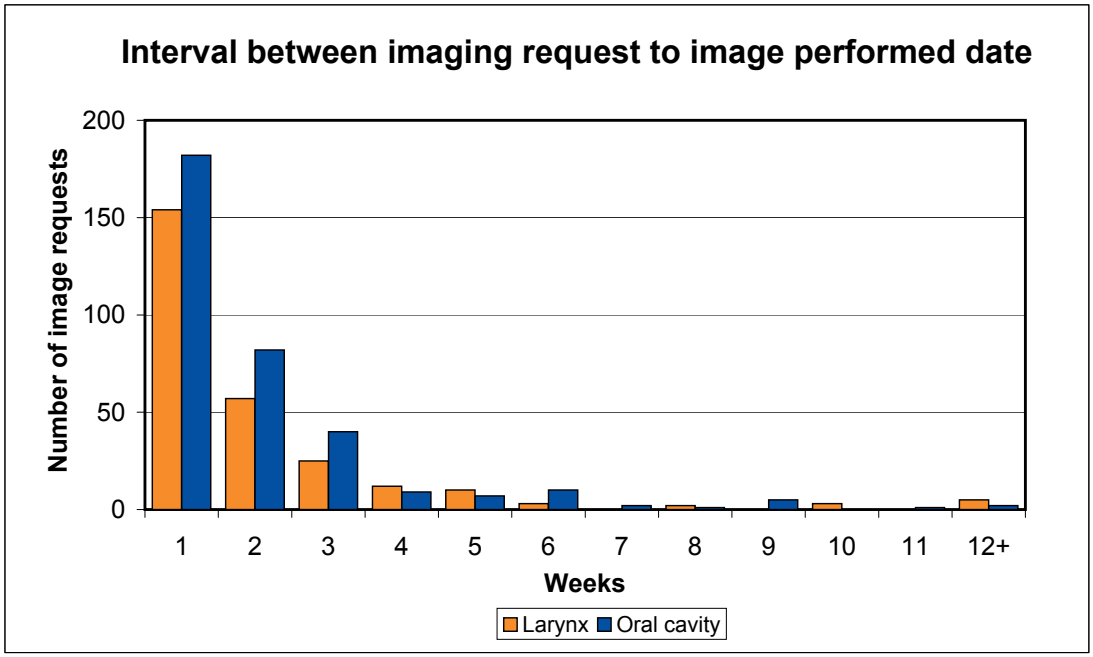


Figure 8.5.11a

8.5.11.1 Imaging types where interval is four weeks or more

Imaging type	Larynx	Oral cavity
X-ray	1	6
CT scan	24	13
MRI scan	6	13
Ultrasound	1	1
Nuclear medicine imaging	0	1
Barium	0	1
Not recorded	3	2
Total	**35**	**37**

Figure 8.5.11.1a

Progression of a patient along the cancer care pathway requires prompt imaging. A significant number of patients' pathways, from the evidence collected, show delays. The figure above demonstrates the imaging requests where a delay greater than four weeks occurred.

A radiologist should be a core member of a multi-disciplinary team MDT and this integration process should accelerate access to imaging. This information will be looked at more robustly in the future.

8.5.12 Interval from diagnosis to first definitive treatment

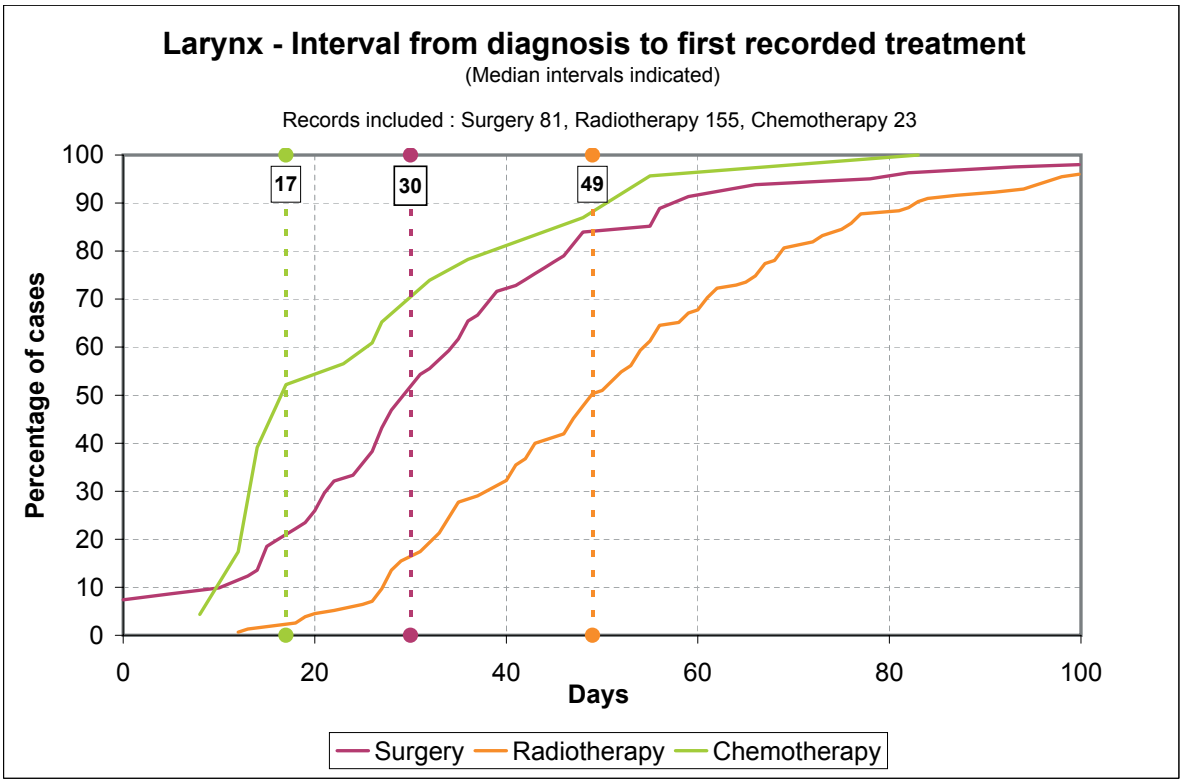


Figure 8.5.12a

- The majority of laryngeal cancer patients' first treatment is primary radiotherapy, with a median time of 49 days from the point of diagnosis. For the smaller number who undergo surgery, the median interval from diagnosis to first recorded treatment is 30 days.

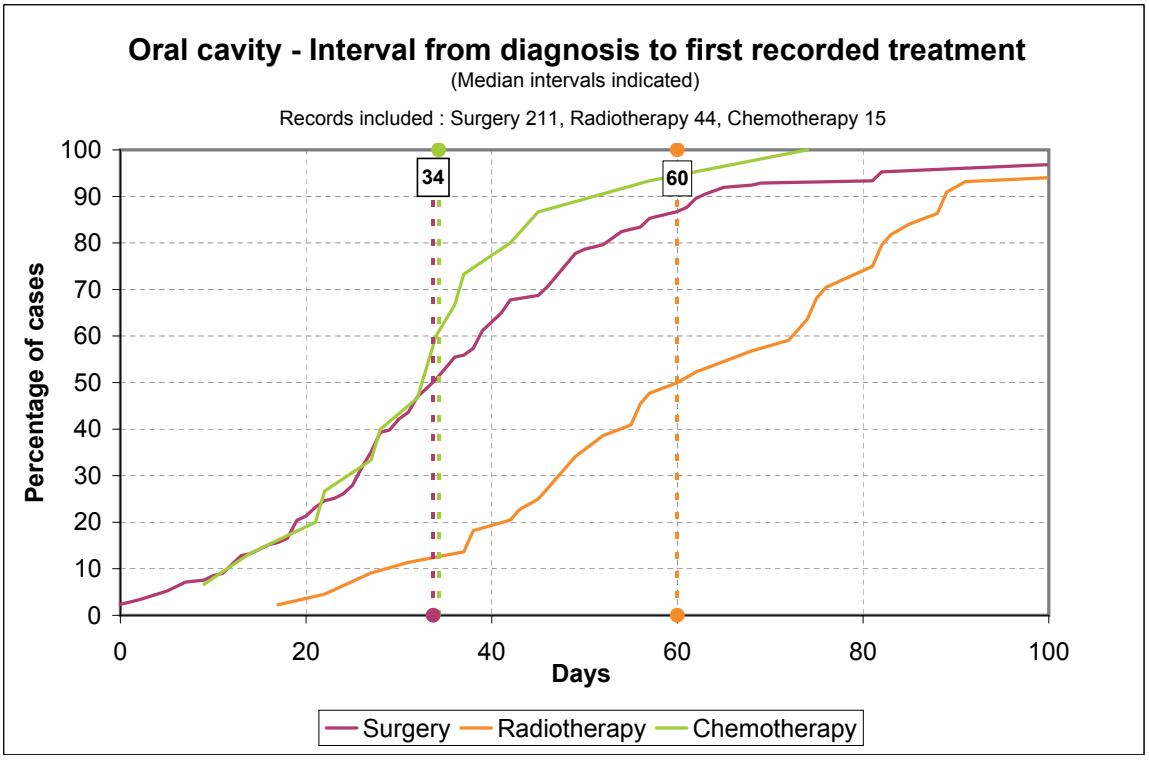


Figure 8.5.12b

The majority of oral cavity cancer patients' first treatment is surgery, with a median time of 34 days from the point of diagnosis. For the smaller numbers who undergo primary radiotherapy, the median interval from diagnosis to first recorded treatment is 49 days.

- The results shown above, highlight that laryngeal and oral cavity cancer patients wait a similar time for radiotherapy, the median time of 49 days is of concern for the ability to reach the 62-day target (from 1 January 2006, patients referred as two-week waits must complete a care pathway from referral to start of first treatment in 62 days).

- Also, of concern, is that 50% of patients are waiting for more than 49 days to commence radiotherapy, which may reflect resource limitations.

This conclusion, that resource limitations particularly apply to radiotherapy, is supported by shorter access times for surgery in comparison for both sub-sites which share the initial common pathway treatment decision.

Best practice suggests that radiotherapy should commence within 28 days of diagnosis[43].

8.5.13 Interval from referral to first definitive treatment

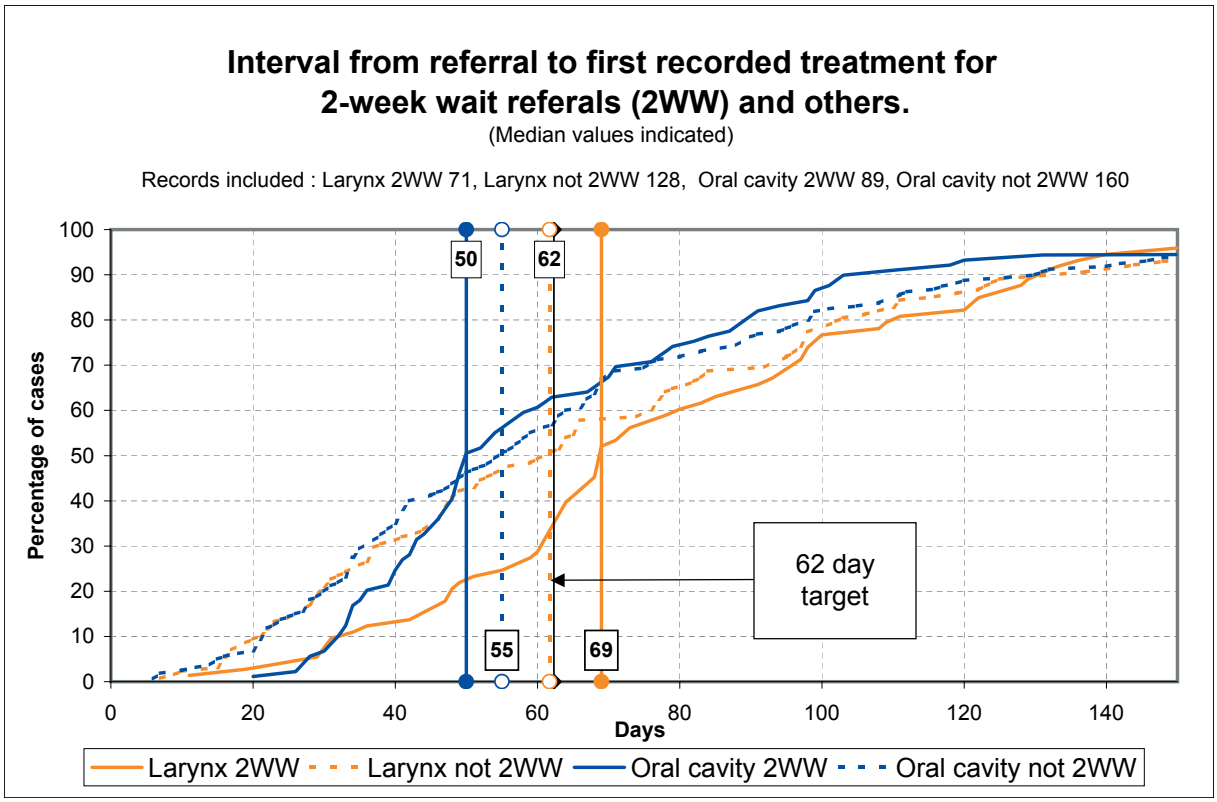


Figure 8.5.13a

The 62-day target came into effect on 1 January 2006 (which is outside of the audit period) and sets an expectation that patients referred under the two-week wait will commence treatment in under 62 days.

- The median interval for larynx patients not referred via the two-week rule was less then 62 days, but for two-week wait patients it was 69 days.
- The median interval for oral cavity by either referral route was under 62 days.

Considerable work remains to achieve this standard for all patients from date of referral to start of treatment.

8.5.14 Interval from surgery date to post-operative radiotherapy

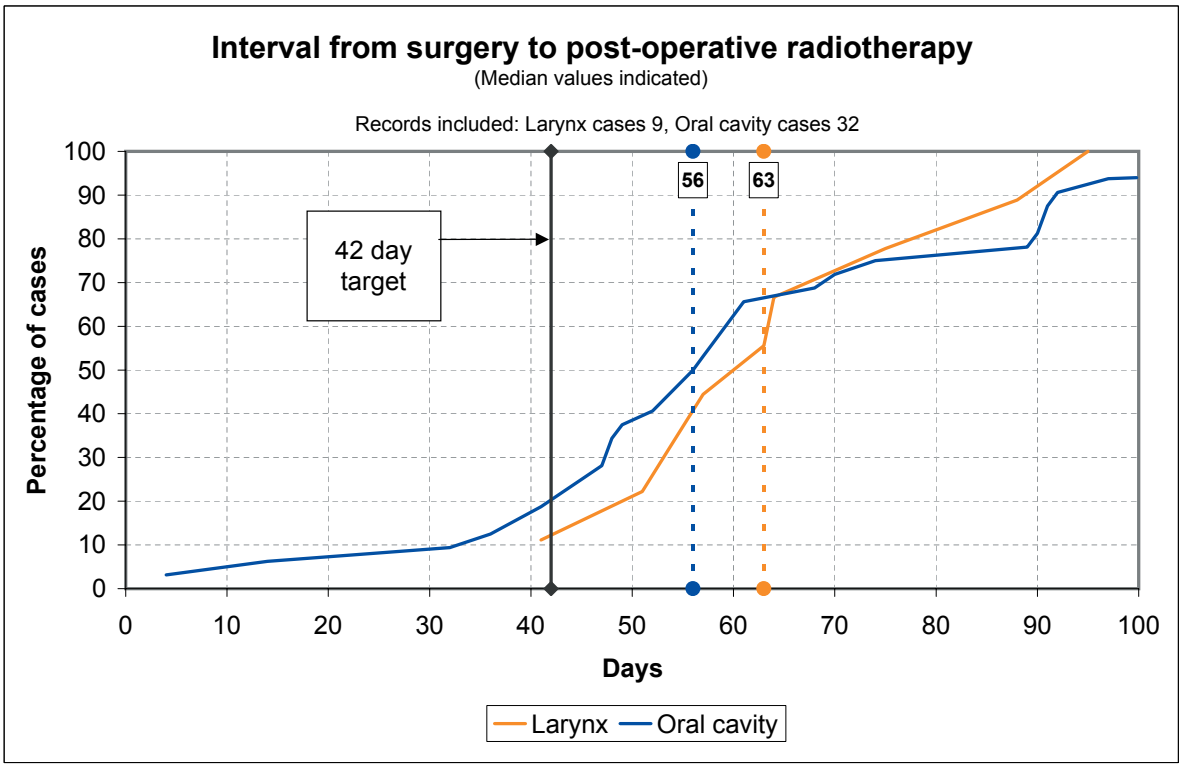


Figure 8.5.14a

- This part of the pathway reflects completion of post surgical healing, confirmation of resective pathology and preparation to proceed to start radiotherapy including production of a mould and planning.

- Tumour biology and previous work suggest that there should be less than six weeks to commencement of radiotherapy following surgery[44]. The results presented suggest considerable delay to commencing radiotherapy following both oral and laryngeal surgery.

Further work is required to assess the contributory elements to this process. Pre-booking of adjuvant radiotherapy at the time of decision to treat may assist in reducing this interval.

8.6 Care provided - squamous cell carcinoma larynx

- 561 cases of larynx cancer were registered onto the DAHNO application.

- 272 (48%) of these cases have either recorded treatment intent or a recorded careplan indicating palliative or supportive care.

First recorded treatment	Early stage	Late stage	Not staged*	Total
Surgery	15	33	40	**88**
Radiotherapy	86	17	46	**149**
Chemotherapy	0	17	1	**18**
Chemotherapy and radiotherapy (same day)	1	3	1	**5**
Specialist palliative care	0	1	9	**10**
Supportive	0	1	1	**2**
Not recorded	95	74	120	**289**
Total cases	**197**	**146**	**218**	**561**

Figure 8.6a

**Not staged – insufficient T, N, M for categorising as early / late*

Note: 272 patient cases have been used as 'the number of cases with recorded treatment' in the calculation of percentages in this section.

The composition of multi-disciplinary teams (MDTs) defines palliative care specialists as a core member.

- The data for this item is deficient in over half of patients not having a primary treatment recorded and due to an absence of staging information.

The established treatment for the majority of patients with laryngeal cancer in England is radiotherapy and this matches to the results shown above.

In advanced disease where appropriate, radical surgery (laryngectomy) with adjuvant radiotherapy is the curative treatment of choice.

In recent years, two new trends have arisen - endolaryngeal surgery for early lesions and organ sparing protocols in advanced lesions.

8.6.1 Percentage having surgical resection with curative intent

- The intent was curative for 78 of the 93 cases with recorded surgery (84%).

- Those with curative surgery make up 28% of the 272 with some recorded treatment, and 14% of the total 561 cases.

- The 15 cases with intent other than curative show: four are with palliative intent, one is with diagnostic intent, one is 'not known' as the intent and nine are with no intent recorded.

8.6.2 Percentage by category of clearance for surgical resection margins

- Only 30% of records contained this information, thus little conclusion can be drawn.

Where laser excision of early lesions has occurred, margins may be much narrower than for open surgery and thus obviate the classification used in data collection.

8.6.3 Percentage having pre-treatment dental assessment

- A pre-treatment dental assessment is recorded for less than 2% of the 561 larynx registrations (eight patients) and is likely to reflect poor data quality.
- This is 3% of the 272 cases with some record of treatment.

The Expert Panel members would hope that this is not a true reflection of practice as it is extremely important to maintain good dental health throughout treatment[45,46].

8.6.4 Percentage having pre-operative / pre-treatment speech and swallowing assessment (includes laser cordectomy) and percentage having pre-operative / pre-treatment (includes radio and chemotherapy) dietetic assessment

- A pre-treatment speech and swallowing assessment is recorded for only 2.5% of the 561 larynx registrations (14 patients) and is likely to reflect poor data quality.
- This is 5% of the 272 cases with some record of treatment.
- A pre-treatment dietetic assessment is recorded for a little over 1% of the 561 larynx registrations (seven patients) and is likely to reflect poor data quality.
- This is 2.5% of the 272 cases with some record of treatment.

Whilst the Expert Panel members believe that this is not a true reflection of current practice, they are aware of countrywide shortages in allied health professional posts to support cancer multi-disciplinary teams (MDTs). The Expert Panel members realise this has significant resource implications, but their view is that speech and language therapists (SALT) and dietetic input is mandatory[47-49]. They hope all MDTs strive to achieve this input. Resource bids would be supported by accurate data collection to quantify deficit, and its correct capture onto the DAHNO application, would identify the national profile of provision.

8.6.5 Percentage receiving each category of surgical procedure (including surgery to neck, surgical voice restoration)

- Eighty-two patients have at least one surgical procedure recorded.

Main categories of operation (patients may be counted in more than one category):

Larynx patients – surgery summary	Count	% of 82 patients with surgery
Microlaryngeal resection	25	30.5
Laryngectomy	39	47.6
• of these 39, the number having neck dissection	31	
• of these 39, number having primary surgical voice restoration	16	
More extensive resection*	5	6.1
• of these five, the number having neck dissection	3	
Neck dissections (including those mentioned with laryngectomy and more extensive resection*)	40	48.8

Figure 8.6.5a

**More extensive resection describes where a portion of the hypopharynx or oropharynx is removed beyond that normally included in a total laryngectomy.*

- Endolaryngeal microsurgical resection accounted for one-third of surgical procedures and its frequency is rising as an alternative to radical radiotherapy in early laryngeal cancer. The audit will monitor this trend with interest.

- 47.6% of surgical procedures were total laryngectomies, with only 41% recorded as having primary surgical voice restoration.

The Expert Panel members would expect that the majority of patients (in excess of 80%) undergoing this procedure would be counselled by a speech and language therapist pre-operatively and be offered primary surgical voice restoration. The availability of speech and language therapists may be a confounding factor but the absence of data collection above (8.6.5a) limits the ability to resolve this.

- A small number of more extensive procedures are identified for very advanced tumours.

8.6.6 Percentage having radical radiotherapy with curative intent

The established treatment for the majority of patients with laryngeal cancer in England is radiotherapy, and this matches the results shown above.

- 167 cases have recorded radical (curative or adjuvant) radiotherapy. This is 95% of the 175 with recorded radiotherapy.
- Those with radical radiotherapy make up 61% of the 272 with some recorded treatment, and 30% of the total 561 cases.
- The eight other cases with recorded radiotherapy break down as: four with palliative intent and four with no intent recorded.
- The majority of patients have radiotherapy as primary treatment or as a planned adjuvant treatment within their initial cancer careplan. However, some patients, having undergone primary surgery, may be advised to proceed to post-operative radiotherapy based on adverse features evident in their resective histology report.

The Expert Panel members have concern that there may be deficiencies in capturing radiotherapy data. This accounts for a small number of patients and thus will be looked at in future reports when sufficient cases have been captured.

8.6.7 Percentage having palliative treatment by type (i.e. radiotherapy, chemotherapy and surgery)

Of those presenting with advanced disease, only small numbers would be expected to get true palliative treatment. It will be of interest in the future to assess what benefit they accrue, and whether they have received this as part of a clinical trial.

- Twelve patients have recorded palliative treatment, 2% of the total 561 registrations, 0.4% of the 272 with recorded treatment.
- The 12 cases break down as: four cases of palliative surgery, four cases of palliative radiotherapy and four cases with palliative chemotherapy.

8.6.8 Percentage having chemotherapy (including categories such as ‘adjuvant’ and ‘neo-adjuvant’)

In the view of the Expert Panel members, there is no currently available evidence supporting the notion that chemotherapy in isolation improves long-term survival in laryngeal cancer[11]. There is, however, some evidence suggesting the benefits of concurrent chemoradiation[50], and again it will be of interest to assess the benefits as they accrue with time.

- The intent was curative, adjuvant or neo-adjuvant for 25 of the 29 cases with recorded chemotherapy (90%).
- These 25 cases are 9% of the 272 with some recorded treatment, and 4% of the total 561 cases.
- The 29 cases with a chemotherapy record are broken down by intent as: 20 curative, two adjuvant, three neo-adjuvant and four palliative.

8.6.9 Percentage referred to specialist palliative care team

There was no data to calculate the percentage referred to the specialist palliative care team.

Specialist palliative care practitioners should be essential members of the core multi-disciplinary team (MDT). Current processes of data capture may not pick up this activity as the provision can occur in a variety of non hospital organisations e.g. community and hospice care. The DAHNO Project Team will be interested to hear about successful methodology to integrate this element of data capture from cancer networks.

8.6.10 Percentage receiving no specific treatment (including active monitoring category)

- 301 larynx cases have no recorded surgery, chemotherapy or radiotherapy.
- Fifteen of these have ‘supportive’ or ‘palliative’ as their careplan intent.
- Nine of the other cases have ‘active monitoring’ as the careplan intent.

8.6.11 Percentage of patients where careplan agreed matches careplan delivered

- 468 of the 561 registrations have a recorded careplan (83%).
- 177 of 468 cases have a treatment record matching the careplan (38%)

Note: Each patient can have more than one careplan and each careplan can list up to four planned treatments. Agreement between careplan and delivery was taken to require a match of every planned treatment in all recorded careplans with a recorded treatment.

8.7 Care provided - squamous cell carcinoma oral cavity

- 477 cases of oral cavity cancer were registered onto the DAHNO application.
- 292 (61%) of these cases have a careplan. This indicates either recorded treatment or a recorded careplan indicating palliative or supportive care.

First recorded treatment	Early stage	Late stage	Not staged*	Total
Surgery	85	70	56	**211**
Radiotherapy	8	21	11	**40**
Chemotherapy	1	8	4	**13**
Chemotherapy and radiotherapy (same day)	1	2	0	**3**
Specialist palliative care	0	14	5	**19**
Supportive	1	3	2	**6**
Not recorded	50	66	69	**185**
Total cases	**146**	**184**	**147**	**477**

Figure 8.7a

**Not staged – insufficient T, N, M for categorising as early / late*
Note: 292 patient cases have been used as 'the number of cases with recorded treatment' in the calculation of percentages in this section.

- The established treatment for the majority of patients with oral cavity cancer in England is primary surgery, and this matches the results shown above.
- As only two-thirds of patients have records of their primary treatment and fewer again have details on the stage of the tumour, data analysis is purely descriptive.

8.7.1 Percentage having pre-treatment dental assessment

- A pre-treatment dental assessment is recorded for 5% of the 477 oral cavity registrations (25 patients).
- This is 8% of the 292 cases with some record of treatment.

The Expert Panel members would hope that this is not a true reflection of practice as it is extremely important to maintain good dental health throughout treatment.[45,46]

8.7.2 Percentage having surgical resection with curative intent

- The intent was curative surgery for 198 of the 211 cases with recorded surgery (94%).
- Those with curative surgery make up 67% of the 292 with some recorded treatment, and 42% of the total 477 cases.
- The 17 cases with intent other than curative break down as: one with palliative intent, two with diagnostic intent and 14 with no treatment intent recorded.

8.7.3 Percentage by category of clearance for surgical resection margins

Percentages of 198 cases recorded surgery with curative intent:

Category	%
Not recorded	50.0
1. Margin involved	3.5
2. <1 mm clear	7.6
3. 1-5 mm clear	22.2
4. > 5 mm clear	12.1
5. Uncertain	1.0
8. Not applicable	3.5

Figure 8.7.3a

- Using the Royal College of Pathologists' guidelines[51], there was evidence in only 12% of cases, of an acceptable clear margin.
- Only 50% of resective pathology records show details on margins of normal tissue around the tumour, which limits the conclusions that can be drawn.
- Adequate resective margins are a predictor of both local recurrence and surgical adequacy[52].
- Of the records completed, one-quarter of them demonstrate margins greater than 5mm.

8.7.4 Percentage having pre-operative speech and swallowing assessment and percentage having pre-operative / pre-treatment dietetic assessment

- A pre-operative speech and swallowing assessment is recorded for 3% of the 477 oral cavity registrations (13 patients).
- This is 4% of the 292 cases with some record of treatment.
- A pre-treatment dietetic assessment is recorded for 1.5% of the 477 oral cavity registrations (seven patients).
- This is 2% of the 292 cases with some record of treatment.

Whilst the Expert Panel members believe that this is not a true reflection of current practice, they are aware of countrywide shortages in allied health professional posts to support cancer multi-disciplinary teams (MDTs). The Expert Panel members realise this has significant resource implications, but their view is that speech and language therapists (SALT) and dietetic input is mandatory. They hope all MDTs strive to achieve this input. Resource bids would be supported by accurate data collection to quantify deficit and its correct capture onto the DAHNO application would identify the national profile of provision.

8.7.5 Percentage receiving each category of surgical procedure (including surgery to neck and flap repair)

Oral cavity patients – surgery summary	Count	% of 191 patients with surgery
Floor of mouth excision	29	15.2
• of these 29, number having neck dissection	17	
Buccal mucosa excision	24	12.6
• of these 24, number having neck dissection	9	
Patients having tongue procedures	49	25.7
• patients having total glossectomy	2	
• patients having partial glossectomy	32	
• patients having excision lesion of tongue	15	
Patients having mandible procedures	41	21.5
• patients having extensive mandibulectomy	1	
• patients having hemimandibulectomy	11	
• patients having marginal mandibulectomy	17	
• patients having mandibulotomy / excision lesion	12	
Partial maxillectomy	9	4.7
Radical neck dissection (includes those listed previously)	20	10.5
Modified neck dissection (includes those listed previously)	28	14.7
Reconstruction with radial forearm flap	26	13.6
Reconstruction mouth with flap	19	9.9

Figure 8.7.5a

- Surgery followed by adjuvant radiotherapy – determined by histological findings is the most common treatment modality for oral squamous cell carcinoma.

- Management of the N0 neck remains a contentious issue, but may be influenced by the requirement to enter the neck for reconstructive options.

8.7.6 Percentage having radical radiotherapy (including brachytherapy, post-operative planned and unplanned)

- Sixty-eight cases have recorded radical (curative or adjuvant) radiotherapy. This is 82% of the 83 cases with recorded radiotherapy.
- Those with radical radiotherapy make up 23% of the 292 with some recorded treatment, and 14% of the total 477 cases.
- The 15 other cases with recorded radiotherapy break down as: 12 with palliative intent and three with no intent recorded.

The majority of patients have radiotherapy as primary treatment or as a planned adjuvant treatment within their initial cancer careplan. Some patients, having undergone primary surgery, may be advised to proceed to post-operative radiotherapy based on adverse features in their resective histology report. The Expert Panel members have concern that there may be deficiencies in capturing radiotherapy data. This accounts for a small number of patients and thus will be looked at in future reports when sufficient cases have been captured.

8.7.7 Percentage having palliative treatment by type (i.e. radiotherapy, chemotherapy, surgery)

- Seventeen patients have recorded palliative treatment, 4% of the total 477 registrations, 6% of the 292 with recorded treatment.
- The 17 cases break down as: one case of palliative surgery, 12 cases of palliative radiotherapy and four cases with palliative chemotherapy.

8.7.8 Percentage having chemotherapy (including categories such as 'adjuvant' and 'neo adjuvant')

In the view of the Expert Panel members, there is no currently available evidence supporting the notion that chemotherapy in isolation improves long-term survival in oral cavity cancer[11]. There is, however, some evidence suggesting the benefits of concurrent chemoradiation[50], and again it will be of interest to assess the benefits as they accrue with time.

- The intent was curative, adjuvant or neo-adjuvant for 18 of the 29 cases with recorded chemotherapy (62%).
- These 18 cases are 6% of the 292 with some recorded treatment, and 4% of the total 477 cases.
- The 29 cases with a chemotherapy record breakdown by intent is: 15 curative, three neo-adjuvant, four palliative and seven with unknown intent.

8.7.9 Percentage referred to specialist palliative care team

- There is no data for this measure.
- Specialist palliative care should be essential members of the core MDT team. Current processes of data capture may not pick up this activity as the provision can occur in a variety of non hospitals e.g. community and hospice care.

8.7.10 Percentage receiving no specific treatment (including active monitoring category)

- 210 oral cavity cases have no recorded surgery, chemotherapy or radiotherapy.
- Twenty-six of these have 'supportive' or 'palliative' as their careplan intent.
- Eight of the other cases have 'active monitoring' as their careplan intent.

8.7.11 Percentage of patients where careplan agreed matches careplan delivered

- 412 of the 477 registrations have a recorded careplan (86%).
- 212 cases of 412 have a treatment record matching the careplan (51%).

Note: Each patient can have more than one careplan and each careplan can list up to four planned treatments. Agreement between careplan and delivery was taken to require a match of every planned treatment in all recorded careplans with a recorded treatment.

8.8 Patient outcomes

8.8.1 One year, two year and three year survival

The audit is too young to provide data for survival analyses.

8.8.2 Locoregional recurrence within one year and two years of diagnosis

The audit is too young to provide data for analysis of recurrence.

8.8.3 Number of treatment related deaths (to include deaths within 30 days of surgery and / or within the same admission)

Description	Larynx	Oral cavity
Number of reported deaths within 30 days of surgery or with discharge destination 'death'	2	4
Of these patients, the number whose death followed recorded surgery with curative intent	0	4
Of the others, number whose death followed recorded surgery with no treatment intent recorded	2	-
Total number of patients with recorded curative surgery	**78**	**198**

Figure 8.8.3a

- Overall, head and neck surgery appears a safe procedure.

Performing complex procedures in a predominantly elderly population with significant co-existent co-morbidities will, however, inevitably lead to some deaths in the peri-operative period[53,54].

Further cycles of the audit will assist in providing nationally derived estimates of risk to patients and multi-disciplinary teams (MDTs).

8.9 Clinical trials

In head and neck cancer, there is a paucity of national and international clinical trials. This remains an important area for development as trials become available.

KEY

N = NETWORK **T** = TRUST **U** = USERS

P = PROFESSIONS **D** = DAHNO PROJECT

Issues	Recommendations	Group to action
9.1 Clinical issues for multi-disciplinary teams (MDTs) A number of issues have been highlighted in the report for which the Expert Panel members had concerns about care delivered based on the data submitted. This may reflect the absence of collection rather than true practice, however teams should assess their local delivery against the items opposite.	Multi-disciplinary teams (MDTs) should locally assess:- - timeliness of pathways - involvement of general dental practitioners and community dental services in awareness of urgent cancer referral processes - that radiologists and specialist palliative care physicians are core members of the MDT - that input to care pathways actively involves speech and language therapists and dieticians - confirming and recording of tumour stage (TNM) prior to care planning - ensure good dental health is maintained throughout treatment - provision of surgical voice restoration counselling pre-treatment to all laryngectomies - provision of swallowing counselling in patients pre-treatment who are about to undergo oral and oropharyngeal reconstructive surgery with free tissue transfer or partial laryngo-pharyngeal surgery - delays in commencement of radiotherapy/ chemotherapy – either as primary or adjunctive treatment - identify and document reasoning for provision of chemotherapy in isolation as first line treatment	**N T U**

Issues	Recommendations	Group to action
9.2 Standards in clinical care		
Absence of nationally accepted clinical standards.	Professional bodies, led by the British Association of Head and Neck Oncologists and facilitated by the DAHNO Project Team, should evolve clinical standards.	P D
9.3 Data quality and completeness		
The public should have access to accurate and risk-adjusted clinical information.	The provision of risk adjustment requires high levels of data quality and completeness - Networks should increase local awareness and encourage compliance with the audit - Trusts should support local provision of data collection not only at commencement of treatment, but through follow up to include data on current treatment and rehabilitation - Users and professionals should contribute to both support data collection and maintain consistency and quality of data collected.	N T U P
Absence of submission completeness on key fields e.g. certainty factor, performance status and comorbidity.	Users should familiarise themselves with all the items detailed within the audit, and use opportunities to attend bi-annual head and neck cancer audit workshops.	U D
25% of potential records submitted. Eight Cancer Networks have no submissions to this first annual report.	All cancer networks and constituent trusts not achieving high levels or any level of case submission should review their processes and support for submission of data. Best practice supporting data collection can be found at **www.dahno.com**	N T
Absence of staging information in submissions.	Awareness of clear recording of staging information prior to care planning should be increased to allow valid future comparison.	N T U P
	All MDTs should be strongly encouraged to complete and validate staging information.	N T U P

Issues	Recommendations	Group to action
9.4 Data process issues		
Continued identification of teams delivering cancer care.	All networks will be regularly contacted by the DAHNO Project Team to confirm contacts at trusts/hospitals that deliver head and neck cancer care.	D N
Absence of data submission on dietetic, speech and language, radiotherapy, palliative care activity.	Organisations should review the data collection process and ensure that it extends across the whole pathway.	N T U
9.5 Application issues		
Iterative changes and updates to application.	Batch release of future application changes, with advance notice to users and training if required.	D U
Uploading from third party systems.	DAHNO Project to advise providers of requirements to achieve successful upload.	D
Reporting of import errors.	DAHNO Project to develop user friendly import log available to local users.	D U

10.1 Risk adjustment

The successful first collection for the head and neck cancer audit has provided a wealth of data. Papers published in peer review medical journals indicate that a number of factors significantly influence outcome in head and neck cancer treatment. These factors include patient demographics, tumour staging, whether the patient lives in an area of deprivation, ability to perform tasks of daily living (performance)[55], and the presence of other illnesses (comorbidity)[26]. Complete and comprehensive data collection allows the start of development of a model to clarify these risks.

To enable us to draw comparative conclusions between cancer networks and teams, it is important that like is compared with like. Both professionals and the public will wish to see evidence that teams are assessing their outcomes in light of evolving standards.

The DAHNO Project Team would strongly encourage collection of the items identified above to ensure, as future reports are produced, the building blocks for risk adjustment are in place.

10.2 Head and neck cancer audit phase II

At inception, the head and neck cancer audit was planned as a phased audit. Continuous data collection year-on-year will permit an expanding assessment of the care of head and neck cancer patients.

Phase I has focused on the **delivery of appropriate primary treatment (including adjuvant therapy) in the management of head and neck cancer affecting the larynx and oral cavity by a multi-professional team, and delivery of care to agreed standards.**

During the data collection period 1 October 2005 to 30 September 2006, the phase I outputs remain unchanged and no additional requirements will be made.

Consultation on phase II outputs, to be introduced in November 2006, has already commenced with the Head and Neck Clinical Reference Group (HNCRG) representing the professional bodies. A consultation document of proposals for phase II will occur prior to the appropriate system development, testing and training.

10.3 Future publications and feedback to users

A summary report is in preparation and will be issued by the end of May 2006. It is intended for a wider audience beyond the professional head and neck community. It will be available on line at **www.dahno.com**

All cancer centres who have submitted sufficient cases by end May 2006 (case number to be decided by the DAHNO Project Team) will receive a local feedback report comparing a selection of outcomes at their cancer centre to the national peer average. This will be sent out between June-July 2006.

Cancer centres with a lower level of submission will receive a letter to confirm contribution.

10.4 UK wide audit

The Healthcare Commission, in agreement with the Welsh Assembly, would like the relevant service providers in Wales to be included in the head and neck cancer audit. Discussions are underway with representatives from Wales to bring about the inclusion of Welsh data within the period of the funded audit, whether through the DAHNO application or through the Welsh cancer information system.

Professional members from elsewhere in the British Isles should be encouraged to participate in the audit where possible. The audit would benefit greatly from the widest possible participation. The NHS Health and Social Care Information Centre (NHS HSCIC) is keen to facilitate and promote discussion and collaboration on national audit, and discussions are taking place to try to ensure commonality of datasets where they are being established outside of England.

Feasibility

National electronic data collection is feasible in the complex arena of head and neck oncology. The head and neck cancer audit has proved it is possible to develop, roll out, acquire and analyse data reflecting the current management of patients with head and neck cancer.

Significant partnerships between professional groupings, the National Clinical Audit Support Programme (NCASP) and the cancer registries have facilitated the rapid development and deployment of the DAHNO application under the sponsorship of the Healthcare Commission.

Contribution rates

The head and neck cancer audit is at an early stage but considerable data has been collected and analysed. With increasing contribution, the accuracy and representative nature of the audit will improve. It offers significant future potential as a powerful tool to improve care and research by identifying strengths and weaknesses and thereby direct resources and modify processes.

Data quality and completeness

Data quality and completeness are crucial to achieve successful audit. It is recognised that increased awareness and feedback to the clinical community will improve data quality and completeness.

Local provision of support to data collection enhances and maintains quality of submission.

All hospitals carrying out head and neck cancer care are to be encouraged to support this endeavour.

Validity

National patterns of care broadly reflect the findings of previous smaller local audits, large case series and consensus reports, suggesting validity. This supports the concept of using high quality clinical databases both for comparative audit and improving delivery of patient care.

Meeting access targets

Analysis of time intervals along the patient pathway suggest that significant changes will have to be implemented if the national access targets for cancer treatments are to be achieved.

Multi-disciplinary team (MDT)

The multi-disciplinary team (MDT) meeting represents a key focal point for data collection.

Two-thirds of recorded patients were confirmed as having been discussed at an MDT meeting. These results may reflect treatment decisions for some patients being made outside of MDTs, which is not ideal.

Data in some areas, e.g. speech and language, dietetic and dental assessment, do not appear to reflect expected national practice. It may be that this data is difficult to capture. Continued review of the data collection process will help to clarify this.

Radiotherapy

Radiotherapy is an integral part of many patients' treatment, either as a sole treatment or following surgery. There is a suggestion that uniform access to radiotherapy is not consistent for all patients, with some experiencing unacceptable delays, but a more comprehensive capture of radiotherapy data will provide more information on this aspect of treatment.

Surgery

Overall, surgery for head and neck cancer treatment appears to be a safe procedure, despite involving complex procedures in a predominantly elderly population with significant
co-morbidities. Further cycles of the audit will assist in providing nationally derived estimates of risk to patients and MDTs.

Appendix 1 List of cancer networks and trusts providing head and neck cancer care in England and participation status

Note: the following represents a list of the cancer networks and their trusts, and the cancer centres within each of the trust that refer, treat or diagnose head and neck cancer patients. We have tried to ensure the list is as comprehensive and accurate as possible, however please let us know if any of the details are incorrect. Some trusts/cancer centres may not be listed where we have been informed that their data will be/is being submitted by another trust/cancer centre.

- Not connected
- Connected, but no patients submitted
- Connected and submitted at least one patient record

Cancer Network Name	Trust Name	Hospital Code	Hospital (Cancer Centre) Name
Derby Burton	Southern Derbyshire Acute Hospitals NHS Trust	RTGFA	Derbyshire Royal Infirmary
	Burton Hospitals NHS Trust	RJF01	Queen's Hospital
Greater Manchester and Cheshire	Christie Hospital NHS Trust	RBV01	Christie Hospital
	Wrightington, Wigan and Leigh NHS Trust	RRF02	Royal Albert Edward Infirmary
	Bolton Hospitals NHS Trust	RMC00	Royal Bolton Hospital
	Salford Royal Hospitals NHS Trust	RM301	Hope Hospital
	Trafford Healthcare NHS Trust	RM401	Trafford General Hospital
	Central Manchester and Manchester Children's University Hospitals NHS Trust	RW3MR	Manchester Royal Infirmary
		RW3DH	The University Dental Hospital of Manchester
	South Manchester University Hospitals NHS Trust	RM202	Wythenshawe Hospital
	Stockport NHS Foundation Trust	RWJ01	Stepping Hill Hospital
	East Cheshire NHS Trust	RJN71	Macclesfield District General Hospital
	Mid Cheshire Hospitals NHS Trust	RBT20	Leighton Hospital
	Tameside and Glossop Acute Services NHS Trust	RMP01	Tameside General Hospital
	Pennine Acute Hospitals NHS Trust	RW604	Rochdale Infirmary
		RW602	North Manchester General Hospital
		RW603	Royal Oldham Hospital
		RW601	Fairfield General Hospital
Humber and Yorkshire Coast	Hull and East Yorkshire Hospitals NHS Trust	RWA01	Hull Royal Infirmary
	Northern Lincolnshire and Goole Hospitals NHS Trust	RJL32	Diana Princess of Wales Hospital
		RJL32	Scunthorpe General Hospital
	Scarborough and North East Yorkshire Health Care NHS Trust	RCC25	Scarborough General Hospital
Lancashire and South Cumbria	Blackpool, Fylde and Wyre Hospitals NHS Trust	RXL01	Blackpool Victoria Hospital
	Morecambe Bay Hospitals NHS Trust	RTXBU	Furness General Hospital
		RTX02	Royal Lancaster Infirmary
	Lancashire Teaching Hospitals NHS Trust	RXN02	Royal Preston Hospital
	East Lancashire Hospitals NHS Trust	RXR02	Blackburn Royal Infirmary
		RXR51	Burnley General Hospital
Merseyside and Cheshire	Clatterbridge Centre for Oncology NHS Trust	REN20	Clatterbridge Hospital Hospital
	North Cheshire Hospitals NHS Trust	RWWWH	Warrington Hospital
	Royal Liverpool and Broadgreen University Hospitals NHS Trust	RQ617	Royal Liverpool and Broadgreen University Hospital
		RQ6	Liverpool University Dental Hospital
	St Helens and Knowsley Hospitals NHS Trust	RBN01	Whiston Hospital
	Aintree Hospitals NHS Trust	REM21	University Hospital Aintree
	Wirral Hospital NHS Trust	RBL14	Arrowe Park Hospital
	Countess of Chester Hospital NHS Foundation Trust	RJR05	Countess of Chester Hospital
	Southport and Ormskirk Hospital NHS Trust	RVY01	Southport and Formby District General Hospital
Northern	North Cumbria Acute Hospitals NHS Trust	RNLAY	Cumberland Infirmary
	City Hospitals Sunderland NHS Trust	RLNGL	Sunderland Royal Hospital
	The Newcastle Upon Tyne Hospitals NHS Trust	RTD01	Freeman Hospital
	South Tyneside Health Care NHS Trust	RE9GA	South Tyneside District Hospital

Cancer Network Name	Trust Name	Hospital Code	Hospital (Cancer Centre) Name
North Trent	Sheffield Teaching Hospitals NHS Foundation Trust	RHQDR	Northern General Hospital
	Barnsley Hospital NHS Foundation Trust	RFFAA	Barnsley Hospital
	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	RP5DR	Doncaster Royal Infirmary
		RP5BA	Bassetlaw Hospital
	Chesterfield Royal Hospital NHS Foundation Trust	RFSDA	Chesterfield Royal Hospital
	Rotherham General Hospitals NHS Trust	RFRPA	Rotherham General Hospital
Teesside, South Durham and North Yorkshire	South Tees Hospitals NHS Trust	RTRAT	James Cook University Hospital
	County Durham and Darlington NHS Trust	RXPDA	Darlington Memorial Hospital
Yorkshire	Leeds Teaching Hospitals NHS Trust	RR813	St James University Hospital
		RR801	The General Infirmary at Leeds
	Bradford Teaching Hospitals NHS Foundation Trust	RAE01	Bradford Royal Infirmary
		RAE05	St Luke's Hospital
	York Hospitals NHS Trust	RCB01	York Hospital
Kent and Medway	Maidstone and Tunbridge Wells NHS Trust	RWF03	Maidstone
		RWF02	Kent and Sussex Hospital
	East Kent Hospitals NHS Trust	RVVKC	Kent and Canterbury Hospital
		RVV09	Queen Elizabeth The Queen Mother Hospital
		RVV01	William Harvey Hospital
	Medway NHS Trust	RPA02	Medway Maritime Hospital
	Dartford and Gravesham NHS Trust	RN707	Darent Valley Hospital
	Queen Victoria Hospital NHS Foundation Trust	RPC04	Queen Victoria Hospital
Mount Vernon	The Hillingdon Hospital NHS Trust	RAS02	Mt Vernon Hospital
		RAS01	Hillingdon Hospital
	West Hertfordshire Hospitals NHS Trust	RWG02	Watford General Hospital
	Heatherwood and Wexham Park Hospitals NHS Trust	RD750	Wexham Park Hospital
	East and North Hertfordshire NHS Trust	RWH01	Lister Hospital
		RWH20	Queen Elizabeth II Hospital (Welwyn)
	Luton and Dunstable Hospital NHS Trust	RC971	Luton and Dunstable Hospital
North East London	Barts and The London NHS Trust	RNJ12	Royal London Hospital
		RNJM0	St Bartholomew's Hospital
		RNJ	London Chest Hospital
	Barking, Havering and Redbridge Hospitals NHS Trust	RF4OC	Oldchurch Hospital
	Homerton University Hospital NHS Foundation Trust	RQXM1	Homerton University Hospital
	Newham Healthcare NHS Trust	RNHB1	Newham University Hospital
	Whipps Cross University Hospital NHS Trust	RGCKH	Whipps Cross University Hospital
North London	Royal Free Hampstead NHS Trust	RAL01	Royal Free Hospital
		RAL16	Royal National Throat Nose and Ear Hospital
	University College London Hospitals NHS Trust	RRV10	University College London
	Barnet and Chase Farm Hospitals NHS Trust	RVLC7	Chase Farm Hospital
	North Middlesex University Hospital NHS Trust	RAPNM	North Middlesex Hospital
	The Princess Alexandra Hospital NHS Trust	RQWG0	Princess Alexandra Hospital
South Essex	Southend Hospital NHS Trust	RAJ01	Southend Hospital
	Basildon and Thurrock University Hospitals NHS Foundation Trust	RDDH0	Basildon Hospital
South West London	The Royal Marsden NHS Foundation Trust	RPY01	Royal Marsden Hospital
	St George's Healthcare NHS Trust	RJ701	St George's Hospital
	Mayday Healthcare NHS Trust	RJ611	Mayday University Hospital
	Epsom and St Helier University Hospitals NHS Trust	RVR50	Epsom Hospital
		RVR05	St Helier Hospital

Cancer Network Name	Trust Name	Hospital Code	Hospital (Cancer Centre) Name
West London	Hammersmith Hospitals NHS Trust	RQN02	Hammersmith Hospital
		RQN01	Charing Cross
		RQN04	Ravenscourt Park Hospital
	West Middlesex University Hospital NHS Trust	RFW01	West Middlesex University Hospital
	North West London Hospitals NHS Trust	RV831	Central Middlesex Hospital
		RV820	Northwick Park Hospital
	Chelsea and Westminster Healthcare NHS Trust	RQM01	Chelsea and Westminster Hospital
	Ealing Hospital NHS Trust	RC368	Ealing Hospital
	Kingston Hospital NHS Trust	RAX01	Kingston Hospital
	St Mary's NHS Trust	RJ501	St Mary's Hospital
3 Counties	Hereford Hospitals NHS Trust	RLQ01	Hereford County Hospital
	Worcestershire Acute Hospitals NHS Trust	RWP31	Kidderminster Hospital
		RWP01	The Alexandra Hospital
		RWP50	Worcester Royal Hospital
	Gloucestershire Hospitals NHS Foundation Trust	RTE01	Cheltenham General Hospital
		RTE03	Gloucester Royal Hospital
Avon Somerset and Wiltshire	East Somerset NHS Trust	RA430	Yeovil District Hospital
	North Bristol NHS Trust	RVJ20	Frenchay Hospital
		RVJ01	Southmead Hospital
	Royal United Hospital Bath NHS Trust	RD130	Royal United Hospital Bath
	Swindon and Marlborough NHS Trust	RN311	The Great Western Hospital
	United Bristol Healthcare NHS Trust	RA709	Bristol Dental Hospital
	Taunton and Somerset NHS Trust	RBA11	Taunton and Somerset Hospital
Dorset	Poole Hospitals NHS Trust	RD300	Poole Hospital
	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	RDZ20	Royal Bournemouth Hospital
	West Dorset General Hospitals NHS Trust	RBD01	Dorset County Hospital
Peninsula	Plymouth Hospitals NHS Trust	RK950	Derriford Hospital
	Royal Devon and Exeter NHS Foundation Trust	RH801	Royal Devon and Exeter Hospital
	Northern Devon Healthcare NHS Trust	RBZ12	North Devon District Hospital
	South Devon Healthcare NHS Trust	RA901	Torbay Hospital
	Royal Cornwall Hospitals NHS Trust	REF12	Royal Cornwall Hospital
Arden	University Hospitals Coventry and Warwickshire NHS Trust	RKB01	Walsgrave Hospital
	George Eliot Hospital NHS Trust	RLT01	George Eliot Hospital
	South Warwickshire General Hospitals NHS Trust	RJC02	Warwick Hospital
Black Country	The Royal Wolverhampton Hospitals NHS Trust	RL403	New Cross Hospital
Leicestershire, Northants and Rutland	University Hospitals Of Leicester NHS Trust	RWEAA	Leicester Royal Infirmary
	Northampton General Hospital NHS Trust	RNS00	Northampton General Hospital
	Kettering General Hospital NHS Trust	RNQ51	Kettering General Hospital
North West Midlands	University Hospital of North Staffordshire NHS Trust	RJE01	University Hospital of North Staffordshire
	Royal Shrewsbury Hospitals NHS Trust	RLZ01	Royal Shrewsbury Hospital
	Mid Staffordshire General Hospitals NHS trust	RJD01	Staffordshire General Hospital
Pan Birmingham	University Hospital Birmingham NHS Trust	RRK02	Queen Elizabeth Hospital
		RRK03	Selly Oak Hospital
	Heart of England NHS Foundation Trust	RR101	Birmingham Heartlands Hospital
	Sandwell and West Birmingham Hospitals NHS Trust	RXK01	Sandwell Hospital
		RXK02	City Hospital
Mid Anglia	Ipswich Hospital NHS Trust	RGQ02	The Ipswich Hospital
	Essex Rivers Healthcare NHS Trust	RDEE4	Colchester General Hospital
		RDEEB	Essex County Hospital
	Mid-Essex Hospital Services NHS Trust	RQ801	Broomfield Hospital
		RQ8LH	St John's Hospital Chelmsford
Norfolk and Waveney	Norfolk and Norwich University Hospital NHS Trust	RM105	Norfolk and Norwich University Hospital
	James Paget Healthcare NHS Trust	RGP75	James Paget Hospital
	Papworth Hospital NHS Foundation Trust	RGM21	Papworth Hospital

Cancer Network Name	Trust Name	Hospital Code	Hospital (Cancer Centre) Name
Thames Valley	Royal Berkshire and Battle Hospitals NHS Trust	RHW01	Royal Berkshire
	Oxford Radcliffe Hospitals NHS Trust	RTH01	The Radcliffe Infirmary
		RTH08	John Radcliffe Hospital
		RTH02	Churchill Hospital
		RTH05	The Horton Hospital
			Oxford Cancer Intelligence Unit
	Stoke Mandeville Hospital NHS Trust		Stoke Mandeville Hospital
	South Buckinghamshire Hospitals NHS Trust	RH250	Wycombe General Hospital
	Milton Keynes General Hospital NHS Trust	RD816	Milton Keynes General Hospital
West Anglia	Addenbrooke's NHS Trust	RGT01	Addenbrooke's Hospital
	Peterborough and Stamford Hospitals NHS Foundation Trust	RGN42	Peterborough District Hospital
	Hinchingbrooke Healthcare NHS trust	RQQ31	Hinchingbrooke Hospital
	Bedford Hospital NHS Trust	RC110	Bedford Hospital
	The Queen Elizabeth Hospital Kings Lynn NHS Trust	RCX01	Queen Elizabeth Hospital (Kings Lynn)
	West Suffolk Hospitals NHS Trust	RGR50	West Suffolk Hospital
Mid Trent	Queen's Medical Centre, Nottingham University Hospital NHS Trust	RFKRA	Queen's Medical Centre, Nottingham University Hospital
	Nottingham City Hospital NHS Trust	RCSLB	Nottingham City Hospital
	Sherwood Forest Hospitals NHS Trust	RK5BC	Kings Mill Hospital
	United Lincolnshire Hospitals NHS Trust	RWDDA	Lincoln County Hospital
		RWDLA	Pilgrim Hospital
		RP7LP	Grantham and District Hospital
Central South Coast	Southampton University Hospitals NHS Trust	RHM01	Southampton General Hospital
	Salisbury Healthcare NHS Trust	RNZ02	Salisbury District Hospital
	Isle of Wight Healthcare NHS Trust	RR201	St Mary's Hospital - Newport
	Royal West Sussex NHS Trust	RPR01	St Richard's Hospital
	Portsmouth Hospitals NHS Trust	RHU03	Queen Alexandra Hospital
		RHU59	Royal Hospital Haslar
South East London	The Lewisham Hospital NHS Trust	RJ224	University Hospital Lewisham
	Guy's and St Thomas' NHS Trust	RJ121	Guy's Hospital
	Bromley Hospitals NHS Trust	RG303	Princess Royal University Hospital Bromley
Surrey, West Sussex and Hants	North Hampshire Hospitals NHS Trust	RN506	North Hampshire Hospital
	Royal Surrey County Hospital NHS Trust	RA201	Royal Surrey County Hospital
	Surrey and Sussex Healthcare NHS Trust	RTP02	Crawley Hospital
		RTP04	East Surrey Hospital
	Frimley Park Hospital NHS Foundation Trust	RDU01	Frimley Park Hospital
	Ashford and St Peter's Hospitals NHS trust	RTK02	Ashford Hospital - o/p only
		RTK01	St Peters Hospital
Sussex	Brighton and Sussex University Hospitals NHS Trust	RXH01	Royal Sussex County Hospital
		RXH09	Princess Royal Hospital Haywards Heath
	Worthing and Southlands Hospitals NHS Trust	RPL04	Worthing Hospital
		RPL03	Southlands Hospital
	East Sussex Hospitals NHS Trust	RXC01	Conquest Hospital
		RXC02	Eastbourne District General Hospital

DAHNO system requirements and recommendations	
Requirement	**Details**
IBM Lotus Notes® version	Release client 6.0 or above
Operating system	Microsoft® Windows 95 Second Edition
	Microsoft® Windows 98
	Microsoft® Windows NT Version 4.0 *(with Service Pack 6a)*
	Microsoft® Windows 2000 Professional Edition
	Microsoft® Windows XP
Protocol	TCP / IP (IBM Lotus Notes® can use other protocols but the DAHNO application is configured for TCP / IP only)
Memory (RAM)	Microsoft® Windows 98 Second Edition – 64mb minimum, 128 mb highly recommended
	Microsoft® Windows 98 – 64 mb minimum, 128mb highly recommended
	Microsoft® Windows NT Version 4.0 (with Service Pack 6a) – 64mb minimum, 128mb highly recommended
	Microsoft® Windows 2000 Professional Edition – 128mb minimum, 256 highly recommended
	Microsoft® Windows XP – 128mb minimum, 256 highly recommended
Disk space	275mb free for IBM Lotus Notes® install
	Additional 750mb required as a minimum for DAHNO application databases
	Total 1gb minimum
Display	Colour monitor and graphics card capable of displaying 1024 x 768 pixels with at least 256 colours

The DAHNO application technical infrastructure is closely linked to the methodology employed in the national heart disease audits – the Central Cardiac Audit Database (CCAD). The success of these audits contributed to the decision to use the same structure for the DAHNO application. The client-server architecture was chosen specifically to overcome the limitations of web-based applications in an environment with poor connectivity. Although the NHS network has improved enormously since CCAD began collecting data in 2000, there are still situations where a client-server system has advantages, for instance when the network is down or the application is installed on a mobile laptop platform with only an occasional NHSnet connection. In addition, software updates are communicated automatically to users when they connect to the central servers to exchange local data, making the systems easy to maintain.

The architecture chosen for the DAHNO application and CCAD has proven robust and secure – there have been no breaches of patient confidentiality since data collection began despite collection of data on nearly a million patients. The level of encryption (of local databases and of data transmissions) ensures database security. The DAHNO/CCAD platform represents the highest level of security in the NHS environment.

Appendix 3 Dataset and manuals

Data collected in DAHNO strictly adheres to the National Cancer Dataset including the head and neck appendage **(www.dahno.com).**

A dataset is a description of the data items, their definitions and the allowable entries that are collected when a patient undergoes an event or procedure. Hospitals have a choice of either entering the minimum amount of data required for oral cavity and larynx (minimum dataset) or entering a wider range of data that will not be analysed by the audit but can be used as reference material by the hospital itself.

The following tables are the dataset items from version 4.0 of the National Cancer Dataset, which has now been updated to version 4.5, for the first phase of the head and neck cancer audit.

Dataset items

ID	Data Item
1	**Demographics**
1.1	NHS number [NHS Number]
1.2	Local patient identifier [Hospital Number]
1.3	Organisation code (code of provider) [Provider Code]
1.4	Carespell identifier [Unique Care Spell Number]
1.5	Patient family or surname [Surname]
1.6	Patient forename of personal name [Forenames]
1.8	Postcode of usual address (at diagnosis) [Postcode at Date of Diagnosis]
1.9	Sex [Sex]
1.10	Birth date [Date of Birth]
1.12	Code of GP practice (Registered GMP) [GP Practice Code]
2	**Referrals**
2.1	Source of referral for cancer [Source of Referral]
2.3	Referral code [Referred by]
2.4	Cancer referral priority type [Priority of Referral]
2.5	Cancer referral decision date [Date of Decision to Refer]
2.6	Referral request received date [Date of Receipt of Referral]
2.9	Date first seen [Date First Seen]
2.10	Delay reason referral to first seen (cancer)
2.11	Delay reason comment (first seen)
2.12	Urgent cancer referral type
2.14	Waiting time adjustment (first seen)
2.15	Waiting time adjustment reason (first seen)
2.16	Source of referral for out-patients
3	**Imaging**
3.2	Clinical intervention date (cancer imaging) [Date of imaging]

ID	Data Item
6.7	TNM category (final pre-treatment) [Overall pre-treatment stage group]
6.8	Staging certainty factor (TNM category) [Certainty factor for TNM stage]
6.10	TNM category (integrated) [Overall Pathological TNM stage grouping - integrated stage]
6.11	T category (integrated stage) [Integrated stage - T category]
6.12	N category (integrated stage) [Integrated stage - N category]
6.13	M category (integrated stage) [Integrated stage - M category]
7	**Surgery and Other Procedures**
7.4	Cancer treatment intent [Treatment intent]
7.5	Decision to treat (surgery) [Date of decision to operate]
7.9	Procedure date [Date of surgery]
7.10	Primary procedure (OPCS) [Main surgical procedure]
7.11	Procedure (OPCS) [Sub-procedure]
7.13	Discharge destination (hospital provider spell) [Discharge destination]
8	**Pathology Details**
8.1	Pathology investigation type [Report Type]
8.3	Investigation result date [Date specimen reported]
8.10	Histology (SNOMED) [Histology]
8.13	Excision margin [Excision Margins]
8.22	Specimen nature [Nature of specimen]
9	**Chemotherapy and other drugs**
9.4	Decision to treat date (Anti-cancer drug regimen) [Date of decision to treat with drug therapy]
9.7	Drug therapy type [Drug therapy type]
9.8	Drug treatment intent [Treatment intent]
9.10	Start date (anti-cancer drug regimen) [Drug treatment start date]

ID	Data Item
3.3	Cancer imaging modality [Imaging Modality]
3.4	Anatomical examination site [Anatomical Site Examined]
4	**Diagnosis**
4.1	Diagnosis date (cancer) [Date of diagnosis]
4.2	Primary diagnosis (ICD) [Primary Site]
4.3	Tumour laterality [Laterality]
4.4	Basis of diagnosis (cancer) [Basis of diagnosis]
4.5	Histology (SNOMED) [Histology]
5	**Cancer Care Plan**
5.1	MDT discussion indicator [Was this cancer care plan discussed at an MDT meeting?]
5.2	Multi-disciplinary team date [The date of the MDT meeting at which the cancer care plan was discussed]
5.3	Careplan agreed date [Cancer care plan date]
5.5	Cancer careplan intent [Cancer care plan intent]
5.6	Planned cancer treatment type [Management modality]
5.7	Treatment type sequence (cancer) [Treatment type sequence]
5.9	Comorbidity index for adults-ACE 27 [Comorbidity index]
5.10	Performance status (adult) [Performance status]
6	**Staging**
6.1	T category (final pre-treatment) [Final pre-treatment T category]
6.2	Staging certainty factor (T category) [Certainty factor for T category]
6.3	N Category (final pre-treatment) [Final pre-treatment N category]
6.4	Staging certainty factor (N category) [Certainty factor for N category]
6.5	M category (final pre-treatment) [Final pre-treatment M category]
6.6	Staging certainty factor (M category) [Certainty factor for M category]

ID	Data Item
10	**Radiotherapy (Teletherapy)**
10.3	Decision to treat date (teletherapy treatment course) [Date of decision to treat]
10.6	Cancer treatment intent [Treatment intent]
10.7	Radiotherapy anatomical treatment site [Anatomical treatment site]
10.8	Start course (teletherapy treatment course) [Teletherapy start date]
11	**Radiotherapy (Brachytherapy)**
11.3	Decision to treat date (Brachytherapy treatment course) [Date of decision to treat]
11.6	Cancer treatment intent [Treatment intent]
11.9	Start date (Brachytherapy treatment course) [Brachytherapy start date]
12	**Palliative Care**
12.1	Decision to treat date (specialist palliative treatment course) [Date of decision to treat]
12.2	Start date (specialist palliative treatment course) [Specialist Palliative Care start date]
13	**Clinical Trials** *Note: Clinical Trials information will be completed for every Clinical Trial in which the patient is involved.*
13.1	Patient trial status (cancer) [Clinical trial status]
14	**Clinical Status Assessment**
14.1	Clinical status assessment date (cancer) [Date of contact]
14.2	Primary tumour status [Primary tumour status]
14.3	Nodal status [Nodal status]
14.4	Metastatic status [Metastatic status]
14.10	Morbidity code (chemotherapy) [Treatment related morbidity]
14.11	Morbidity code (radiotherapy) [Treatment related morbidity]
14.12	Morbidity code (combination) [Treatment related morbidity]
15	**Death Details**
15.1	Death date [Date of death]

Site specific dataset items

ID	Data Item	Description	Codes and Classifications
HN.11	Symptoms first noted date [Date symptoms first noted]	The month/year the patient first noted any symptoms related to the site of cancer. This can be an approximate date	Date format of mm/yyyy. If the month is not known it is usual to choose the middle of the year e.g. 06/1999
HN.19	Contact date (Dietician initial) Date of first assessment with dietician	The date that the patient was first assessed by a dietician	Date format
HN.20	Date communication sent to primary care following care plan agreed	This is the date of sending of notification of the care plan details to primary care following the care plan being agreed with the patient	Date format
HN.21	Date of image request (cancer imaging)	The date on which imaging is requested that contributes to pre-treatment staging	Date format
HN.22	Date of first pre-treatment dental assessment	Within the care spell this is the date of the first dental assessment by a dentally qualified practitioner, which contributes to preparation for treatment	Date format
HN.23	Date of first contact with speech and language therapist	Within the care spell this is the date of the first contact with a qualified speech and language professional which contributes to preparation for treatment	Date format

DAHNO application manuals

The following set of manuals are available on **www.dahno.com** under 'Guidance for New Users':

- DAHNO Guide to the Data Manual
- Introduction: Volumes 1-5
- Volume 1: Summary Guide
- Volume 2: System Administration
- Volume 3: Explaining Data Collection
- Volume 4: Using DAHNO
- Volume 5: Online Reports and Analysis
- DAHNO Data Manual v1.1
- DAHNO Subset of Cancer Dataset 4.0 v1.0

AGREED BY BAHNO AUDIT AND DATASET GROUP AND THE HEAD AND NECK CLINICAL REFERENCE GROUP

VERSION 1.0 FEBRUARY 2003

DEMOGRAPHY, CASEMIX AND SOCIO-ECONOMIC STATUS

1.1 Number of patients registered per year with new head and neck primaries of the larynx and oral cavity (divided into the total seen by the specialist team and the local 'denominator' population derived from all available sources)
1.2 Age and sex distributions
1.3 Distribution of stage at point of treatment decision, and final definitive staging to include pathological TNM (pTNM) (including 'C' certainty factor relating to TNM stage and date of staging)
1.4 Distribution of performance status at point of treatment decision
1.5 Presence or absence of significant comorbidity at index point of diagnosis (ACE-27)
1.6 Distribution of diagnosis, treatment and outcome by socio-economic super-group, derived from the postcode

2. DIAGNOSTIC AND STAGING PROCESS, WAITING TIMES

2.1 Source of referral to specialist team (2ww v non 2ww)(primary v secondary)
2.2 Interval from first symptom to referral to specialist team
2.3 Time to first appointment from referral
2.4 Time to diagnosis from referral
2.5 Time from biopsy to its reporting
2.6 Time to decision to treat from diagnosis, expressed as:
2.6a Time to MDT ('triage' date) from diagnosis
2.6b Time to careplan date agreed from diagnosis
2.6c Time to sending communication to primary care from date careplan agreed
2.7 % discussed at MDT meeting
2.8 % with histological confirmation prior to cancer careplan
2.9 % with staging information recorded at time of cancer careplan
2.10 % having chest imaging by CXR or CT prior to cancer careplan
2.11 Time from decision to make imaging request to reporting for imaging (CT / MRI) contributory to pre-treatment staging complying with college guidelines
2.12 Time to first definitive treatment from diagnosis
2.13 Time from surgical resection to histological reporting on resective specimen
2.14 Time from referral to first definitive treatment
2.15 Time from date of surgery to first treatment for post-operative radiotherapy

3. TREATMENT: SQUAMOUS CELL CARCINOMA LARYNX – all cancer sites

(Recognising the need to record more than one treatment modality if applicable)

3.1 % having surgical resection with curative intent
3.2 % by category of clearance for surgical resection margins
3.3 % having pre-treatment dental assessment
3.4 % having pre-operative speech and swallowing assessment (includes for laser cordectomy)

3.5 % having pre-operative / pre-treatment (includes radio and chemo therapy) dietetic assessment
3.6 % receiving each category of surgical procedure (including surgery to neck and surgical voice restoration)
3.7 % having radical radiotherapy (including post operative planned and unplanned)
3.8 % having palliative treatment by type (i.e. radiotherapy, chemotherapy and surgery)
3.9 % having chemotherapy (including categories such as 'adjuvant' and 'neo adjuvant')
3.10 % referred to specialist palliative care team
3.11 % receiving no specific treatment (including active monitoring category)
3.12 % patients where careplan agreed matches careplan delivered

4. TREATMENT: SQUAMOUS CELL CARCINOMA ORAL CAVITY – all cancer sites

(Recognising the need to record more than one treatment modality if applicable)

4.1 % having pre-treatment dental assessment
4.2 % having surgical resection with curative intent
4.3 % by category of clearance for surgical resection margins
4.4 % having pre-operative speech and swallowing assessment
4.5 % having pre-operative / pre-treatment dietetic assessment
4.6 % receiving each category of surgical procedure (including surgery to neck)
4.6b type of flap repair (if applicable)
4.7 % having radical radiotherapy (including brachytherapy, post-operative planned and unplanned)
4.8 % having palliative treatment by type (i.e. radiotherapy, chemotherapy and surgery)
4.9 % having chemotherapy (including categories such as 'adjuvant' and 'neo adjuvant')
4.10 % referred to specialist palliative care team
4.11 % receiving no specific treatment (including active monitoring category)
4.12 % patients where careplan agreed matches careplan delivered

5. PATIENT OUTCOMES

5.1 1 year survival (survival to be expressed in a variety of ways including age-adjusted all-cause mortality and disease-specific mortality – which will require the recording of cause of death and source of this information)
5.2 2 year survival
5.3 5 year survival
5.4 Number (%) of treatment related deaths (to include death within 30 days of surgery and / or within the same admission)
5.5 Locoregional recurrence within 1 year and 2 years of diagnosis (by treatment and tumour type - which will require recording of recurrence by type)

6. CLINICAL TRIALS

6.1 % entered into national clinical trials at cancer careplan

TNM Classification of Malignant Tumours – Fifth Edition 1997 – Edited by L.H. Sobin and Ch. Wittekind - John Wiley and Sons Inc. Publication

Larynx (ICD-10 C32.0, 1, 2, C10.1)

Anatomical Sites and Subsites

1 **Supraglottis (C32.1)**
   (i) Suprahyoid epiglottis [including tip, lingual (anterior) (C10.1), and laryngeal surfaces]
   (ii) Aryepiglottic fold, laryngeal aspect
   (iii) Arytenoid
   (iv) Infrahyoid epiglottis
   (v) Ventricular bands (false cords)
2 **Glottis (C32.0)**
   (i) Vocal cords
   (ii) Anterior commissure
   (iii) Posterior commissure
3 **Subglottis (C32.2)**

TNM Clinical Classification

T - Primary Tumour

TX Primary tumour cannot be assessed
T0 No evidence of primary tumour
Tis Carcinoma in situ

Supraglottis

T1 Tumour limited to one subsite of supraglottis with normal vocal cord mobility
T2 Tumour invades mucosa of more than one adjacent subsite of supraglottis or glottis or region outside the supraglottis (e.g., mucosa of base of tongue, vallecula, medial wall of piriform sinus) without fixation of the larynx
T3 Tumour limited to larynx with vocal cord fixation and / or invades any of the following: postcricoid area, pre-epiglottic tissues, deep based tongue
T4 Tumour invades through the thyroid cartilage and / or extends into soft tissues of neck, thyroid and / or oesophagus

Glottis

T1	Tumour limited to vocal cord(s) (may involve anterior or posterior commissure) with normal mobility
T1a	Tumour limited to one vocal cord
T1b	Tumour involves both vocal cords
T2	Tumour extends to supraglottis and / or subglottis, and / or with impaired vocal cord mobility
T3	Tumour limited to larynx with vocal cord fixation and / or invades paraglottic space, and / or with minor thyroid cartilage erosion (e.g. inner cortex)
T4	Tumour invades through the thyroid cartilage and / or extends to other tissues beyond the larynx, e.g., trachea, soft tissues of the neck, thyroid, pharynx

Subglottis

T1	Tumour limited to subglottis
T2	Tumour extends to vocal cord(s) with normal or impaired mobility
T3	Tumour limited to larynx with vocal cord fixation
T4	Tumour invades through cricoid or thyroid cartilage and / or extends to other tissues beyond the larynx, e.g., trachea, soft tissues of the neck, thyroid, pharynx

N - Regional Lymph Nodes

NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis in a single ipsilateral lymph node, 3cm or less in greatest dimension
N2	Metastasis in a single single ipsilateral lymph node, more than 3cm but not more than 6cm in greatest dimension; or in multiple ipsilateral lymph nodes, none more than 6cm in greatest dimension; or in bilateral or contralateral lymph nodes, none more than 6cm in greatest dimension
N2a	Metastasis in a single ipsilateral lymph node, more than 3cm but not more than 6cm in greatest dimension
N2b	Metastasis in multiple ipsilateral lymph nodes none more than 6cm in greatest dimension
N2c	Metastasis in bilateral or contralateral lymph nodes, none more than 6cm in greatest dimension
N3	Metastasis in a lymph node more than 6cm in greatest dimension

M – Distant Metastasis

MX	Distant metastasis cannot be assessed
M0	No distant metastasis
M1	Distant metastasis

Stage Grouping

Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage II	T2	N0	M0
Stage III	T1, T2 T3	N1 N0, N1	M0 M0
Stage IV A	Any T	N2 N0, N1, N2	M0 M0
Stage IV B	Any T	N3	M0
Stage IV C	Any T	Any N	M1

Oral cavity (ICD-10 C02 – C06)

Anatomical Sites and Subsites

1 **Buccal Mucosa**
   (i) Mucosa of upper and lower lips (C00.3,4)
   (ii) Cheek mucosa (C06.0)
   (iii) Retromolar areas (C06.2)
   (iv) Bucco-alveolar sulci, upper and lower (vestibule of mouth) (C06.1)
2 **Upper alveolus and gingiva (upper gum) (C03.0)**
3 **Lower alveolus and gingiva (lower gum) (C03.1)**
4 **Hard palate (C05.0)**
5 **Tongue**
   (i) Dorsal surface and lateral borders anterior to vallate papillae (anterior two-thirds) (C02.0,1)
   (ii) Inferior (ventral) surface (C02.2)
6 **Floor of mouth (C04)**

TNM Clinical Classification

T - Primary Tumour

TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Tis	Carcinoma in situ
T1	Tumour 2cm or less in greatest dimension
T2	Tumour more than 2cm but not more than 4cm in greatest dimension
T3	Tumour more than 4cm in greatest dimension
T4	(oral cavity) Tumour invades adjacent structures e.g., through cortical bone, into deep / extrinsic muscle of the tongue, maxillary sinus, or skin of face

N - Regional Lymph Nodes

NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis in a single ipsilateral lymph node, 3cm or less in greatest dimension
N2	Metastasis in a single single ipsilateral lymph node, more than 3cm but not more than 6cm in greatest dimension; or in multiple ipsilateral lymph nodes, none more than 6cm in greatest dimension; or in bilateral or contralateral lymph nodes, none more than 6cm in greatest dimension
N2a	Metastasis in a single ipsilateral lymph node, more than 3cm but not more than 6cm in greatest dimension
N2b	Metastasis in multiple ipsilateral lymph nodes none more than 6cm in greatest dimension
N2c	Metastasis in bilateral or contralateral lymph nodes, none more than 6cm in greatest dimension
N3	Metastasis in a lymph node more than 6cm in greatest dimension

M - Distant Metastasis

MX	Distant metastasis cannot be assessed
M0	No distant metastasis
M1	Distant metastasis

Stage Grouping

Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage II	T2	N0	M0
Stage III	T1, T2	N1	M0
	T3	N0, N1	M0
Stage IV A	Any T	N2	M0
		N0, N1, N2	M0
Stage IV B	Any T	N3	M0
Stage IV C	Any T	Any N	M1

Appendix 6 Adult Comorbidity Evaluation (ACE-27) UK Values

Note: The following form was developed as an extract from the National Cancer Dataset v4.0. We acknowledge that the intellectual property rights remain with Washington University in St. Louis, Campus Box 8013, 660 So. Euclid Avenue, St. Louis, MO 63110. It originates from and was developed with the permission of Washington University in St. Louis.

Date _____
Coder's Initials _____
Oncology Center _____
Accession # _____

Adult Comorbidity Evaluation-27 -- UK

Identify the important medical comorbidities and grade severity using the index.
Overall Comorbidity Score is defined according to the highest ranked single ailment, except in the case where two or more Grade 2 ailments occur in different organ systems. In this situation, the overall comorbidity score should be designated Grade 3.

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Cardiovascular System			
Myocardial Infarct	MI ≤ 6 months	MI > 6 months ago	Old MI by ECG only, age undetermined
Angina / Coronary Artery Disease	Unstable angina	Chronic exertional angina Recent (≤ 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty (PTCA) Recent (≤ 6 months) coronary stent	ECG or stress test evidence or catheterization evidence of coronary disease without symptoms Angina pectoris not requiring hospitalization CABG or PTCA (>6 mos.) Coronary stent (>6 mos.)
Congestive Heart Failure (CHF)	Hospitalized for CHF within past 6 months Ejection fraction < 20%	Hospitalized for CHF >6 months prior CHF with dyspnea which limits activities	CHF with dyspnea which has responded to treatment Exertional dyspnea Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	Ventricular arrhythmia ≤ 6 months	Ventricular arrhythmia > 6 months Chronic atrial fibrillation or flutter Pacemaker	Sick Sinus Syndrome
Hypertension	DBP≥130 mm Hg Severe malignant papilledema or other eye changes Encephalopathy	DBP 115-129 mm Hg DBP 90-114 mm Hg while taking antihypertensive medications Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	DBP 90-114 mm Hg while not taking antihypertensive medications DBP <90 mm Hg while taking antihypertensive medications Hypertension, not otherwise specified
Venous Disease	Recent PE (≤ 6 mos.) Use of venous filter for PE's	DVT controlled with Coumadin or heparin Old PE > 6 months	Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	Bypass or amputation for gangrene or arterial insufficiency < 6 months ago Untreated thoracic or abdominal aneurysm (≥6 cm)	Bypass or amputation for gangrene or arterial insufficiency > 6 months ago Chronic insufficiency	Intermittent claudication Untreated thoracic or abdominal aneurysm (< 6 cm) s/p abdominal or thoracic aortic aneurysm repair
Respiratory System			
	Marked pulmonary insufficiency Restrictive Lung Disease or COPD with dyspnea at rest despite treatment Chronic supplemental O_2 CO_2 retention (pCO_2 > 6.7 kPa) Baseline pO_2 < 6.7 kPa FEV1 (< 50%)	Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities FEV1 (51%-65%)	Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment FEV1 (66%-80%)
Gastrointestinal System			
Hepatic	Portal hypertension and/or esophageal bleeding ≤ 6 mos. (Encephalopathy, Ascites, Jaundice with Total Bilirubin > 34 mmol/l)	Chronic hepatitis, cirrhosis, portal hypertension with moderate symptoms "compensated hepatic failure"	Chronic hepatitis or cirrhosis without portal hypertension Acute hepatitis without cirrhosis Chronic liver disease manifested on biopsy or persistently elevated bilirubin (>51 mmol/l)
Stomach / Intestine	Recent ulcers (≤ 6 months ago) requiring blood transfusion	Ulcers requiring surgery or transfusion > 6 months ago	Diagnosis of ulcers treated with meds Chronic malabsorption syndrome Inflammatory bowel disease (IBD) on meds or h/o with complications and/or surgery
Pancreas	Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	Uncomplicated acute pancreatitis Chronic pancreatitis with minor complications (malabsorption, impaired glucose tolerance, or GI bleeding)	Chronic pancreatitis w/o complications

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Renal System			
End-stage renal disease	Creatinine > 265 umol/l with multi-organ failure, shock, or sepsis Acute dialysis	Chronic Renal Insufficiency with creatinine >265 umol/l Chronic dialysis	Chronic Renal Insufficiency with creatinine 177-265 umol/l
Endocrine System	**(Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)**		
Diabetes Mellitus	Hospitalization ≤ 6 months for DKA Diabetes causing end-organ failure, including retinopathy, neuropathy, nephropathy*, coronary disease*, or peripheral arterial disease*	IDDM without complications Poorly controlled AODM with oral agents	AODM controlled by oral agents only
Neurological System			
Stroke	Acute stroke with significant neurologic deficit	Old stroke with neurologic residual	Stroke with no residual Past or recent TIA
Dementia	Severe dementia requiring full support for activities of daily living	Moderate dementia (not completely self-sufficient, needs supervising)	Mild dementia (can take care of self)
Paralysis	Paraplegia or hemiplegia requiring full support for activities of daily living	Paraplegia or hemiplegia requiring wheelchair, able to do some self care	Paraplegia or hemiplegia, ambulatory and providing most of self care
Neuromuscular	MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living	MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care	MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care
Psychiatric			
	Recent suicidal attempt Active schizophrenia	Depression or bipolar disorder uncontrolled Schizophrenia controlled w/ meds	Depression or bipolar disorder controlled w/ medication
Rheumatologic	**(Incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)**		
	Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)	Connective Tissue Disorder on steroids or immunosuppressant medications	Connective Tissue Disorder on NSAIDS or no treatment
Immunological System	**(AIDS should not be considered a comorbidity for Kaposi's Sarcoma or Non-Hodgkin's Lymphoma)**		
AIDS	Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)	HIV+ with h/o defining illness. $CD4^+ < 200/$ L	Asymptomatic HIV+ patient. HIV^+ w/o h/o AIDS defining illness. $CD4^+ > 200/$ L
Malignancy	**(Excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)**		
Solid Tumour including melanoma	Uncontrolled cancer Newly diagnosed but not yet treated Metastatic solid tumour	Any controlled solid tumour without documented metastases, but initially diagnosed and treated within the last 5 years	Any controlled solid tumour without documented metastases, but initially diagnosed and treated > 5 years ago
Leukemia and Myeloma	Relapse Disease out of control	1^{st} remission or new dx <1yr Chronic suppressive therapy	H/o leukemia or myeloma with last Rx > 1 yr prior
Lymphoma	Relapse	1^{st} remission or new dx <1yr Chronic suppressive therapy	H/o lymphoma w/ last Rx >1 yr prior
Substance Abuse	**(Must be accompanied by social, behavioral, or medical complications)**		
Alcohol	Delirium tremens	Active alcohol abuse with social, behavioral, or medical complications	H/o alcohol abuse but not presently drinking
Illicit Drugs	Acute Withdrawal Syndrome	Active substance abuse with social, behavioral, or medical complications	H/o substance abuse but not presently using
Body Weight			
Obesity		Morbid (i.e., BMI ≥ 38)	

OVERALL COMORBIDITY SCORE (Circle one.) **0** None **1** Mild **2** Moderate **3** Severe **9** Unknown

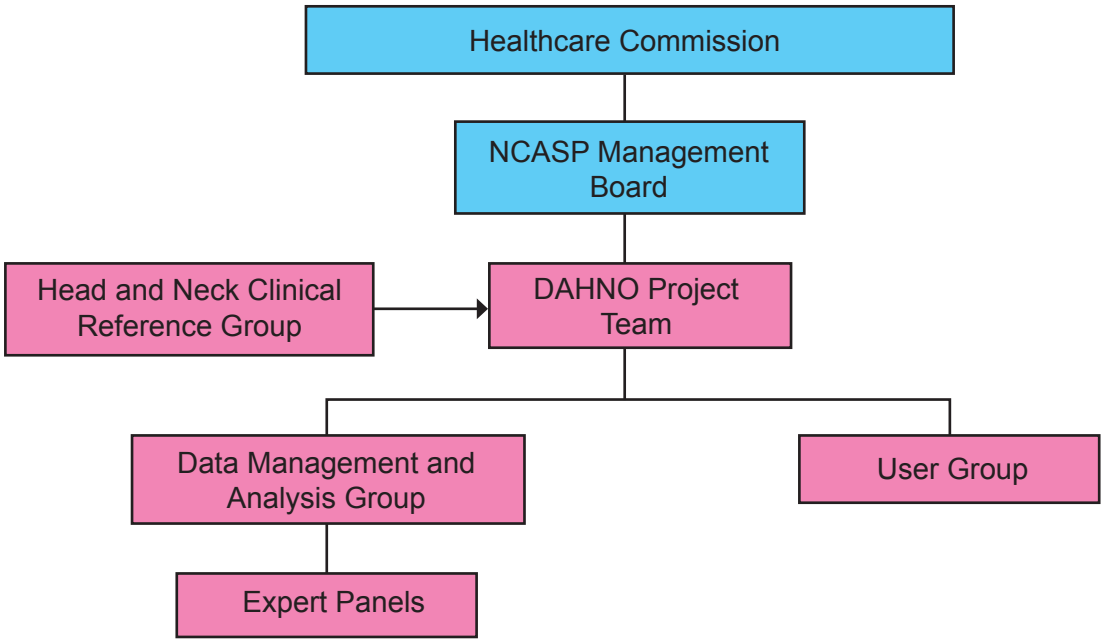
Appendix 7 Contributing professional organisations

There are many organisations that have contributed and continue to contribute to the audit. They are listed below.

British Association of Head and Neck Oncologists
British Association of Head and Neck Oncology Nurses
British Association of Oto-larynologists - Head and Neck Surgeons (ENT UK)
British Association of Oral and Maxillofacial Surgeons
British Association of Plastic Surgeons
British Dental Association
British Dietetic Association
British Society for Oral and Maxillofacial Pathology
National Association of Laryngectomee Clubs
Royal College of Surgeons
Royal College of General Practitioners
Royal College of Radiologists
Royal College of Pathologists
Royal College of Speech and Language Therapists
Palliative Care Association
Let's Face It Charity
UK Association of Cancer Registries
Representatives from clinical oncology
Representatives from clinical psychology

Appendix 8 Project structure and membership

Project structure:



Parties involved in the head and neck cancer audit:

NCASP Management Board	The NCASP Management Board has management responsibility for the NCASP Programme and all Project Implementation Groups and Service Management Groups
Project Team	**Remit:** Provides the overall direction for the service and manages the delivery of the project. They manage the issues and risks as well as change requests, maintain the link to SUS to develop the requirements and assist facilitation of migration, agree communication objectives and link to the Communication Team to ensure communication delivery. The Board is accountable for the success of the Project and is responsible for the management of all Project groups. **Accountable to:** The NCASP Management Board **Representation:** Healthcare Commission, lead head and neck cancer clinicians, project manager, audit system developer, cancer registries, Cancer Action Team, DAHNO User Group, DAHNO Helpdesk, Clinical Oncology **Meeting frequency:** Monthly **Membership:** Richard Wight-Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam-Consultant Maxillofacial Surgeon (Project Team Vice Chair), Annamarie O'Connor-DAHNO Project Manager, Steve Dean-Senior Project Manager (Cancer Audits), Helen Laing-Clinical Audit Commissioning Manager, Ronnie Brar-DAHNO Developer, Simon Netley-Helpdesk Support Manager, Chris Carrigan-National Lead for cancer registries, John Browne-Lecturer in Outcome Assessment, Phil Hill-Cancer Action Team, Chris Nutting-Consultant and Hon. Senior Lecturer in Clinical Oncology, David Cunningham-CCAD Project Manager, Natasha Hinds-Payne-DAHNO Project Support Officer

Head and Neck Clinical Reference Group	**Remit:** Agreement and ownership of the outcome measures and related data items; provision of support to the Project Team; 'marketing' of the DAHNO Audit (across the professions involved); and governance of use of the data and nature of reporting **Accountable to:** The Project Team and their professional bodies **Representation:** National groups involved in head and neck cancer care **Meeting frequency:** Two meetings per year **Membership:** Richard Wight-Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam-Consultant Maxillofacial Surgeon (Project Team Vice Chair), Annamarie O'Connor-DAHNO Project Manager, Steve Dean-Senior Project Manager (Cancer Audits), Natasha Hinds-Payne-DAHNO Project Support Officer, Ian Martin-Oral and Maxillofacial Surgeon-British Association of Head and Neck Oncologists, Patrick Bradley-Head and Neck Oncologic Surgeon, Andrew Fishburn-British Association of Head and Neck Oncology Nurses, John Weighill-British Association of Otolaryngology, Head and Neck Surgeons / MCN, Andrew Brown-British Association of Oral and Maxillofacial Surgeons, Sarah Cameron-British Dietetic Association, Paul Speight-British Society for Oral and Maxillofacial Pathology, RD Errington-Clinical Oncology, Gerry Humphris-Clinical Psychology Helen Laing-Healthcare Commission Dr Gerry Robertson-Lead Clinician for Scotland head and neck cancer data, Christine Piff-Let's Face It, Jean Fraser-National Association of Laryngectomee clubs, Ged Corcoran-Palliative Care Association, Dr AJ Downes-Royal College of General Practitioners, Dr JFC Olliff-Royal College of Radiologists, Tim Helliwell-Royal College of Pathologists, Jo Patterson-Royal College of Speech and Language Therapists, Clem Brown-UKACR-United Kingdom Association of Cancer Registries, John Browne-RCSEng CEU, Professor Mike Richards-National Cancer Director-Cancer Action Team, Martin Old-NCASP Programme Manager
Data Management and Analysis Group	**Remit:** To manage requests for data received by the DAHNO Project and the analysis of data collected as well as delivering the annual report and trust analysis reports and feedback **Accountable to:** The Project Team **Representation:** Lead clinicians, project manager, cancer registries, data analysis specialist, IC Caldicott Guardian **Meeting frequency:** Four to five meetings per year **Membership:** Richard Wight-Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam-Consultant Maxillofacial Surgeon (Project Team Vice Chair), Annamarie O'Connor-DAHNO Project Manager, Steve Dean-Senior Project Manager (Cancer Audits), Helen Laing- Clinical Audit Commissioning Manager, Ronnie Brar-DAHNO Developer, Chris Carrigan-National Cancer Registration Coordinator, Henrik Møller-National Lead for cancer registries, Andy Pring-Senior Information Analyst, Sandra Edwards-Cancer Intelligence Analyst, Patrick Bradley-Head and Neck Oncologic Surgeon, Christine Piff-CE Let's Face It charity, Jo Patterson-Macmillan Speech and Language Therapist, John Brown-Lecturer in Outcome Assessment, Doug Errington-Clinical Oncologist, Patrick Magennis, Consultant Oral and Maxillofacial Surgeon, Natasha Hinds-Payne-DAHNO Project Support Officer

Expert Panels	**Remit:** To provide clinical expertise for the development of the annual reports **Accountable to:** The Data Management and Analysis Group **Representation:** Lead clinicians in oral cavity and larynx cancer, Cancer Registries **Meeting Frequency:** Two to three times per year **Membership:** Patrick Bradley-Head and Neck Oncologic Surgeon, Martin Birchall-ENT Surgeon, Mark Watson-ENT Surgeon, David Howard-ENT Surgeon, Jon Hayter-Consultant Maxillofacial Surgeon, Cyrus Kerawala-Consultant Oral and Maxillofacial Surgeon, Simon Rogers-Consultant Maxillofacial Surgeon and Honorary Reader in OMFS, Christine Harling-Head of Information at cancer registries, Chris Nutting-Consultant and Hon. Senior Lecturer in Clinical Oncology, Richard Wight-Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam-Consultant Maxillofacial Surgeon (Project Team Vice Chair), Annamarie O'Connor-DAHNO Project Manager, Natasha Hinds-Payne-DAHNO Project Support Officer
User Group	**Remit:** To ensure the views of users are appropriately reflected in the DAHNO Project **Accountable to:** The Project Team **Representation:** Users spanning all types of job role related to head and neck cancer audit at a cancer network and trust level nationwide **Meeting frequency:** Quarterly **Membership:** Ann Archibald-Cancer Data Coordinator-Heatherwood and Wexham Park Hospitals Trust, Susan Sterland-MDT Data Coordinator-UHL, Sarah Raheem-Head and Neck Data Manager-Royal Marsden NHS Foundation Trust, Andy Burns-Consultant Consultant Oral and Maxillofacial Surgeon-Sunderland Royal Hospital, Anne Allen-Cancer Control Audit Manager-Derby Hospitals NHS Foundation Trust, Jane Johnson-Clinical Audit Facilitator-Norfolk and Waveney Cancer Network, Tracey Church-Head and Neck Oncology/ Tracheostomy Service Secretary-James Paget Healthcare NHS Trust, Michele Moore-Cancer Information Analyst-Sussex Cancer Network, Claire Barralet-Cancer Data Manager-Arrowe Park Hospital, Sian Haynes-Cancer Integration Engineer-Royal Sussex County Hospital, Richard Wight-Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam-Consultant Maxillofacial Surgeon (Project Team Vice Chair), Annamarie O'Connor-DAHNO Project Manager, Ronnie Brar-DAHNO Developer, Natasha Hinds-Payne-DAHNO Project Support Officer, Gary Sargent-DAHNO Helpdesk, Sandy Garrity-DAHNO Helpdesk
Helpdesk	**Remit:** To respond to and manage technical and clinical queries from users and provide ad hoc training and support to networks and trusts **Accountable to:** The DAHNO Project Team **Team members:** Gary Sargent and Sandy Garrity
NCASP Team	NCASP Team including Programme Manager Martin Old and NCASP Communications Manager Lynne Skyrme
Early adopters	Trusts within the following cancer networks were early adopters for the rollout of the DAHNO application: Northern; Teesside and Yorkshire; West Anglian; Arden; Avon, Somerset and Wiltshire; and North London
Previous staff	Beverley Meeson, Steve Wise, Toby Hewlett, Steven Cooper and Rob Cairney
Other contributors	Jonathan Boyce, Dick Waite and Katy Evans at the Healthcare Commission

2 WW – two-week wait

ACE 27 – adult comorbidity evaluation scale of 27 items

Adjuvant – a treatment given in concert with another to boost its activity

Aetiology – part of medical science dealing with the causes of disease

Alveolus – the portion of the jaw containing the teeth

Aspiration – withdrawal of fluids or gases from a cavity

BAHNO – British Association of Head and Neck Oncologists

Biopsy – removal and examination of tissue for diagnostic purposes

Brachytherapy – treatment modality using implantation of radioactive material

Buccal mucosa – mucous membrane of the mouth or inside of cheek

Cancer centre – specialised unit within a single or multiple hospitals that refers, diagnoses and treats cancer patients

Cancer site – area where cancer located within the head and neck

Careplan – represents the point in the patient pathway where a plan of treatment is proposed and thus an appropriate point to assess and record a patient's fitness

CDS – community dental service

CEU – Clinical Effectiveness Unit

CHART – continuous hyper fractionated accelerated radiotherapy

Chemoradiation – a combination of chemotherapy and radiotherapy

Chemotherapy – drugs used in the treatment of cancer

Child document – sub-document of parent document

Comorbidity – co-existent illness(es) to the disease under consideration

Csv – comma separated value

CT scan – computerised tomography scan – a radiological investigation

Curative – intending to cure

CXR – chest x-ray

Cytologist – specialist in cytology

Cytology – study of cells and disease

DAHNO – DAta for Head and Neck Oncology

DAHNO application – software to collate head and neck cancer comparative audit data

Dataset – collection of data items

Deprivation – absence of expected level of social provision

DH – Department of Health

Diagnosis – confirming the presence of a disease

Dietician – Allied Health Professional specialising in aspects of nutrition

Dorsal – top surface

DSCN – dataset change notice

Early adopter – team or individual taking up a new idea ahead of majority

Endolaryngeal – treatment of the larynx via a hollow endoscope

Endoscopy – visualisation of hollow organs

ENT – ear, nose and throat

Epidemiologist – specialist in the study of prevalence of disease

Excision – removal of an area of tissue

Extensive resection – extension of surgical procedure to remove greater volume of tissue than normally required for named procedure

GDP – general dental practitioner

Gingiva – mucosal tissue between and around teeth

Glossectomy – removal of the tongue

Glottis – vocal cords

GMP – general medical practitioner

GP – general practitioner

Healthcare Commission – an independent body, to promote and drive improvement in the quality of healthcare and public health in England and Wales.

Hemimandibulectomy – removal of half the mandible

Histology – microscopic study of cells and tissues

Histopathologist – specialist in histology and pathology

HNCRG – Head and Neck Clinical Reference Group

Homogeneous – of similar consistency

IBM Lotus Domino® – the server architecture upon which the central DAHNO application database replica resides

IBM Lotus Notes® – the client software that renders the functionality of the DAHNO database to its users

ICD-10 – International Classification of Diseases version 10 IMD - index of multiple deprivation

IOG – Improving Outcomes Guidance

ISB – Information Standards Board

Laryngeal – of the larynx

Larynx – voice box-anatomic cartilage and soft tissue structure

LDP – Local Delivery Plans

Lesion – abnormal area of tissue

Linear accelerator – radiotherapy machine to deliver high energy beam to treat cancer

Locoregional – area surrounding tumour and its expected lymph node drainage

Lymph node – a bean shaped focus of lymphoid tissue present in many areas of the body forming part of the immune system

M stage – distant metastasis

Malignant – cancerous

Mandibulectomy – removal of mandible

Mandibulotomy – division of mandible, usually for surgical access

Maxillectomy – removal of maxilla

Maxillofacial – of face and jaws

MDT – multi-disciplinary team

Meta-analysis – statistical technique to summate separate statistical analyses

Metastasis – distant spread of tumour

MRI – magnetic resonance imaging

Mucosa – mucous membrane

Multi-modality – combination of treatments

N stage – regional lymph node metastasis

NCASP – National Clinical Audit Support Programme

NCDS – National Cancer Dataset

Neo-adjuvant – a substance given ahead of another treatment to boost its effect

Neoplasm – new growth of tissue in part of body

NHS HSCIC – NHS Health and Social Care Information Centre

NHSIA – NHS Information Authority

NICE – National Institute for Clinical Excellence

NOS – not otherwise specified

NSF – National Service Framework

Oncologists – non surgical specialists in cancer management

ONS – Office of National Statistics

Oral cavity – 'the mouth': anatomic area bounded by the lips palate and pharynx

Osteoradionecrosis – breakdown of bone as a consequence of previous radiotherapy

Palate – 'roof of the mouth' comprising bony anterior portion and soft tissue portion posteriorly

Palliative care – care to alleviate a disease without intent of cure

Parent document – document that has subdocuments beneath it

PAS – Patient Administration System

Pathology – study of organs of the body in disease

Pathway – describes stages in journey of care for a disease

PCT – primary care trust

Pharynx – anatomic area from back of nose to start of oesophagus (gullet)

Prognosis – predicted outcome of a disease

Radiologist – imaging specialist

Radiotherapy – cancer treatment using high energy beams

RCT – randomised controlled trials

Resective pathology – pathology of a surgically removed specimen

SALT – speech and language therapists

Squamous cell carcinoma (SCC) – the commonest cancer of mucous membranes in the head and neck

Stage certainty – validation of diagnostic method used to derive stage of cancer

Subglottis – area of voice box below vocal cords

Supraglottis – upper portion of voice box above vocal cords

SUS – Secondary User Services

SWAHN – South West Audit of Head and Neck Cancer

T stage – extent of primary tumour

Teletherapy – high-energy external beam used in the treatment of cancer

Thorax – chest cavity

TNM – Tumour, Node, Metastasis Clinical Classification of anatomical extent of cancer

Tomography – multiple slice x-ray

Triage – preliminary assessment to determine future pathway of care

Tuberculosis – infectious granulomatous disease

Tumour – swelling or abnormal growth

UICC – International Union Against Cancer

Ulceration – erosion of a mucosal lining

Ultrasonography – technique of high frequency sound scans to visualise body structures

Upper aero-digestive tract – anatomic area from nose and mouth to start of gullet, includes both respiratory passages (nose and voice box) as well as mouth and pharynx

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