National Head and Neck Cancer Audit

Key findings for England and Wales for the audit period October 2006 to November 2007

DAHNO third annual report

Prepared in partnership with:

Healthcare Commission
British Association of Head and Neck Oncologists
National Head and Neck Cancer Audit

Key findings for England and Wales for the audit period November 2006 to October 2007

This third report for the National Head and Neck Cancer Audit presents data collected on new registrations from 1 November 2006 to 31 October 2007 and treatment data up to the 19 November 2007. The report reflects the analysis of that data, and provides recommendations for improving data quality and completeness. DAHNO, by means of a continuous electronic audit on the management of head and neck cancer in England and Wales, aims to provide comparative feedback to NHS Provider Trusts, with the ultimate aim of improving patient care.

A brief summary report will compliment this report following its publication.

Electronic copies of this report can be found at: www.ic.nhs.uk/canceraudits


Printed copies of this report can be ordered from The NHS IC for health and social care’s (The IC) Contact Centre 0845 300 6016 or email: enquiries@ic.nhs.uk quoting document reference 28010408.

For further information about this report, contact The NHS IC’s Contact Centre 0845 300 6016 or email: enquiries@ic.nhs.uk
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Foreword

I welcome this third annual report of the National Head and Neck Cancer Audit. I am delighted that case ascertainment across England and Wales has risen and that completeness of data on staging has improved. However, with only two thirds of incident cases being reported there is clearly a need for further improvement. In particular, those organisations which have yet to contribute data should now make this a priority.

The Cancer Reform Strategy for England, published in December 2007, emphasises the importance of complete and accurate information as a driver for quality improvement. Comparative information can help clinical teams to identify areas where action needs to be taken to improve performance and outcomes. Information is also needed for strong commissioning and by patients who wish to make informed choices.

This audit provides useful information on the average intervals between diagnosis and treatment for patients with laryngeal and oral cancer. This should provide a useful baseline for Trusts in England as they prepare to achieve the waiting time targets set out in the Cancer Reform Strategy.

Professor Mike Richards CBE
National Cancer Director

Considerable progress has been made in overall case ascertainment. The central role of the MDT meeting with multi professional discussion and agreement of a care plan for each newly diagnosed patient supported by collection of clinical data, as emphasised in this report, must remain priorities.

Whilst case ascertainment has dropped a little this year, case ascertainment for the Welsh Cancer Networks remains very good and may be due to the fact that our national cancer information system, CANISC, is also used to collect and report on the 31/62 day waiting times targets. Our next priority is to improve on recording the stage of disease. During 2008 roll out will commence of on-screen histopathology reporting that will feed directly into CANISC. We expect this will make a significant improvement that will be reflected in future National Head and Neck Cancer Annual Reports.

Dr Jane Hanson
Advisor for Cancer Services to the Wales Assembly Government and Director of the Cancer Services Co-ordinating Group
The third annual report, examines data submitted from November 2006 until October 2007. Milestones have been achieved with over 2,000 cases of larynx and oral cavity cancer submitted this year and over 4,500 since the inception of the audit in 2004. 34 out of 36 networks are now actively submitting data across England and Wales.

The aim of the audit remains to achieve comprehensive and consistent data collection producing meaningful results, that provide a vehicle to improve delivery of care to patients with head and neck cancer. The benefits section sets out some of the achievements so far and will expand as the audit progresses.

The success of the audit is dependent on contributions made by individual clinicians and their support staff across the country. This annual report represents their continuing labours, facilitated and supported by NHS Provider Trusts and Cancer Networks.

This audit benefits from the knowledge and commitment of the National Clinical Audit Support Programme (NCASP) team, and the continued support of the Healthcare Commission.

For patients, the third report has extensive sections showing, for the first time, trust identifiable information and this will be expanded in future years.

Further pieces of the complex puzzle of head and neck cancer care have been revealed, and as comprehensive submissions continue to rise, a more complete picture of head and neck cancer will emerge. This report is another stride along this road.

Richard Wight FRCS
Consultant Head and Neck Surgeon
National Head and Neck Cancer Audit Project Chair

Graham Putnam FRCS
Consultant Head and Neck Surgeon
National Head and Neck Cancer Audit Project Vice Chair
1 Executive Summary

The National Head and Neck Cancer Audit third annual report on the management of head and neck cancer in England and Wales includes a brief background to head and neck cancer (Section 2) and a description of the infrastructure, methods and analysis used within the audit (Section 3, 4 and 7).

Benefits and improvements and benefits from the audit and detailed recommendations are in sections 5 and 6.

Detailed findings in section 8 cover outcomes in both carcinoma of the larynx and oral cavity.

The third annual report includes a wide variety of outcomes provided in a trust identifiable format for the first time.

Throughout the document significant points for consideration are shown in shaded green boxes, whilst practical examples of methods that improve data collection and collation can be found in the Good Practice Example boxes and at: www.ic.nhs.uk/canceraudits.

Submission by Provider Trust/Cancer Network is found in section 1, as well as listing those organisations who submit on behalf of other trusts.

1.1 What is DAHNO?

DAHNO (Data for Head and Neck Oncology), provides a continuous electronic comparative audit on management of head and neck cancer. It is supported by professional bodies and funded by the Healthcare Commission.

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

Core issues addressed in the first phase of the audit 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.

1.2 What DAHNO adds to existing information

To confirm the quality of care delivered, anonymised data on individual patients needs to be collected and analysed. The head and neck cancer audit, 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.

In the third annual report the following findings are reported in Trust identifiable format:

- Participation
- Number of new larynx and oral cavity cancer primaries
- Percentage of those cases submitted with T and N category recorded
- Interval from biopsy to reporting
- Percentage of cases discussed at MDT
- Interval from diagnosis to MDT
- Interval from diagnosis to first definitive treatment (radiotherapy and surgery).

1.3 Where head and neck cancer care happens - submission rates

1.3.1 Contributing Cancer networks in England and Wales

The third annual report covers the period 1 November 2006 to 31 October 2007. Each of the 36 Cancer Networks in England and Wales have had an opportunity to contribute.

2 networks failed to submit any cases - North London Cancer Network and South East London Cancer Network.

31 English Cancer Networks and all 3 Welsh Cancer Networks have submitted patient records, and the third annual report describes results for over 2,000 patient records – a 50 per cent increase. 13 Cancer Networks have managed to achieve high levels of registration with in excess of 90 per cent of the expected case numbers recorded.
Executive Summary

1.3.2 Overview of case ascertainment

The data collection period (12 months) showed a rise in case ascertainment to 67 per cent (2,035 of an estimated 3,032 cases in England and Wales). In England, 1,882 cases of an estimated 2,820 cases were submitted (67 per cent) which is a significant rise with improved data completeness particularly on staging.

In Wales, 153 cases of an estimated 212 cases were submitted (72 per cent), which is a high level but with varying data completeness.

Whilst the improved case ascertainment is welcomed, executive teams in organisations yet to contribute should ensure prioritisation of head and neck cancer in their audit programmes. Participation in the head and neck cancer audit is part of the Healthcare Commission's Annual Health Check, and the peer review process continuing in 2008.

Complete and comprehensive submission provides a vehicle for assurance to trust boards and patient groups of the quality of care delivered in head and neck cancer. Additionally with complete data submission it will become possible to identify areas where action is required to ensure that care is improved to the highest standards.

1.4 Key overall findings

1.4.1 The pivotal role of the multi disciplinary (MDT) meeting

Patient expectations and Improving Outcomes Guidance (IOG) are that all care discussions are made at a MDT, and head and neck cancer teams need to provide assurance to Trust boards on this aspect of care delivery.

93 per cent of submitted cases were confirmed as having been discussed at a multidisciplinary meeting (this represents 74 per cent of patients submitted).

A small but significant number (5.8 per cent) were recorded as not having been discussed.

A number of providers have higher than average rates of non discussion and the project team will be alerting those organisations where high levels of not discussed are recorded to consider the reasons for this and to develop improvement plans.

20 per cent did not have this important item recorded, from which is not possible to be certain on the overall national discussion rate which could lie in the range 74 to 93 per cent. This still leaves doubt that treatment decisions for patients could be being made outside of MDTs.

1.4.2 Speech and language and dietetic provision

Pre-treatment speech and swallowing and dietetic assessment recording has improved but still only for a small percentage of registrations and is likely to reflect poor data quality. Whilst the expert panel members believe that this is not a true reflection of current practice, they are aware of nationwide shortages in allied health professional roles to support cancer MDTs. Patient representatives feel it is imperative that speech and swallowing and dietetic support is available to all patients with head and neck cancer from the point of diagnosis to enhance patient care.

1.5 Who receives the care?

1,045 cases of larynx cancer and 986 cases of oral cavity cancer were submitted.

Cancer of the larynx and oral cavity is again shown as a disease of older age groups in the pooled data of 46 months of data collection (90 per cent greater than 50 years old) with males predominating.

1.5.1 The patient journey

Consideration of submitted data and informal feedback from expert panels, demonstrates general dental practitioners do not appear to be embracing the two week rule referrals pathway in some networks and in others are not actively involved in the referral process. One in five oral cavity cancer patients are referred via the general dental practitioner/community dental service route, but of these only a quarter are via the two week wait urgent referral pathway. The networks need to examine local pathways and their effective usage.

Understanding is growing of factors responsible for recognition of signs and symptoms in patients that encourage a visit to a doctor or dentist. Furthermore, the variation of the interval from first recognition of suspicious symptoms to diagnosis, as shown by this audit, beg questions of the psychological response to possible malignancy, not only by patients but also care-givers.
There are several methods of obtaining a biopsy in order to reach a diagnosis, and the most appropriate method will be determined by the clinical presentation. The median time from biopsy to its reporting is 3 days for larynx and 4 days for oral cavity, which is an improvement. However, it is noted that 24 per cent of oral cavity cases reported have an interval greater than 10 days. This is shown by provider trust and confirms this represents both a delay in a small number of organisations and a variation within providers. To improve the patient pathway process mapping may identify areas where delays in the whole pathway could be reduced (from taking of a biopsy, through to its reporting). Manpower issues within pathology, and in particular head and neck pathology, remain a challenge.

A smaller number of patients show delays in diagnostic imaging, which is an improvement from the first report. Local teams should assess the timeliness of imaging and seek to reduce delay if applicable.

The investigation of cancer wait times was expected to reduce patient journey times, whilst median time has reduced in the study period, considerable work remains to achieve these targets for all patients. Booked care and clearly defined patient pathways are key factors to minimise delay. The site specific group should see performance reporting as a routine agenda item, supported by monitored action plans if avoidable delay is evident.

1.5.2 Care provided

In the treatment of laryngeal cancer patients, radiotherapy remains the most common first treatment. However, a previously noted trend in treatment via endolaryngeal resection, has not continued this year. The current evidence base does not support the superiority of one treatment over another. DAHNO provides a unique opportunity to track this and other treatment changes in a high quality clinical database containing sufficient information to allow casemix adjusted outcomes.

For surgery, the median interval from diagnosis to first recorded treatment is 25 days but for those undergoing primary radiotherapy a median time of 45 days was found, showing no reduction in comparison to the second annual report. An analysis by provider trust shows wide variation in intervals within organisations as well as between organisations for radiotherapy.

The majority of oral cavity patients have surgery as a first treatment with a median time to operation of 33 days from diagnosis. For the smaller number who undergo primary radiotherapy the median interval to commencement of treatment is 52 days. An analysis by provider trust shows wide variation in intervals within organisations as well as between organisations for surgery.

The interval to commencing radiotherapy has remained static, as highlighted in last year’s report, this still suggests that head and neck cancer patients continue to have difficulty in accessing radiotherapy services. Provider organisations for radiotherapy should review patient pathways, as well as the resource committed to head and neck cancer, with the aim of avoiding unnecessary delays.

The Expert Panels noted the importance of collection of actual care delivered along the whole patient pathway and that this is currently inadequate, to allow proper assurance in the complex multi professional management of head and neck cancer.

1.6 Recommendations

The third analysis has again demonstrated variability in record completeness between different organisations and between individual records. High levels of submission and completeness of records are required to gain the most value from the audit. NHS Provider Trusts and Cancer Networks should facilitate data collection through the MDT by providing resources, training and direction.

Trusts, MDTs and site specific groups should review the recommendations below and develop action plans using the soon to be released action planning tool for any deficiencies.

Trusts, MDTs and Cancer Networks should as a priority:

- Develop a local action plan based on the findings in the audit using the action planning tool that has been developed by the National Head and Neck Cancer Audit team.
- Ensure that Cancer Networks reflect on where variation in access occurs within the network
as identified in trust identifiable data and seek to examine pathways that underpin it.

- Ensure that tumour staging (TNM) is confirmed and recorded prior to care planning and following surgical procedures.

- Facilitate meeting patient expectations that all care discussions are being made at a MDT, and head and neck cancer teams need to provide assurance around this important aspect of care delivery. This is unanimously supported by the Expert panels.

- Ensure that all Cancer Networks and constituent Provider Trusts not achieving high levels or any level of case submission review their processes and support for submission of data. Best practice supporting data collection can be found at: www.ic.nhs.uk/canceraudits.

- Ensure that all MDTs seek to accurately capture resective pathology information including pathological stage for every patient undergoing surgical treatment. This will enable true stage comparison of outcomes.

- Ensure that Provider Trusts uploading information via CSV commence preparation of CSV requirements to meet Phase II as well as attending future workshops.

Full details of all recommendations from the report can be found in Section 6.2. This should be used by organisations when formulating local action plans.

1.7 Key aspects for the current collection year November 2007 – October 2008

Future versions of this annual report will increase reporting of outcomes by contributory provider trust and team, thus the importance of routine collection of factors that contribute to risk adjustment to allow true comparisons to be made (stage, co-morbidity and performance status).

The index year cohort currently reported will be used to apply casemix adjustment and to develop a casemix adjustment model for the fourth report.

Phase II has commenced and extends the audit to cover a wider range of anatomic sites (nasopharynx, oropharynx, hypopharynx and major salivary glands) a wider range of pathologies and a more in depth assessment of multi-professional involvement (surgical voice restoration, dietetic and clinical nurse specialist).

For Phase II a new system infrastructure is available – web DAHNO, and more information can be found at www.ic.nhs.uk/canceraudits.

1.8 Good Practice

This year it has been possible to capture good practice happening across England and Wales which results in achieving excellent standards of care, case ascertainment and data quality. From this it has been possible to identify key factors which, if present, increase benefits gained by an organisation from participation in the audit.

Key factors influencing improvements in case ascertainment and data quality are:

- A committed clinical team who understand the benefits and requirements of the audit
- Close working between clinical and administrative staff in a supporting environment
- Dedicated administrative staff to capture data and provide data quality checks
- Close working relationships with the information and IT departments to maximise the use of technology in data capture and validation
- Systems and processes to check (ideally by clinicians) data to be entered into DAHNO.

Whilst there is still room for improvement, data completeness, levels of case ascertainment and data quality have improved significantly for a number of performance measures to be shown at trust level and have been incorporated into this report.

This report has included examples of good practice case studies showing how organisations have achieved good results.

1.9 Summary report

A summary report is in preparation and will be issued following the publication of this report. Its focus is for wider audience beyond the professional head and neck community. It will be available on line at: www.ic.nhs.uk/canceraudits
1.10 Participating Trusts

The data quality calculation can be found in Appendix 9.

The score if all expected cases are submitted with all index events is 100. An allowance is made for diagnostic only centres in comparison to diagnostic and treatment centres. A poor level of data completeness is recorded if a score of less than 26 is achieved, and reflects, for example 50 per cent of estimated cases with 50 per cent completeness. A submission of under five cases automatically records poor data completeness.

Figure 1.10 Participating Trusts

<table>
<thead>
<tr>
<th>KEY</th>
<th>Good Data Completeness</th>
<th>Poor Data Completeness</th>
<th>Not participating in 2006-2007 audit period</th>
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3 Counties Cancer Network
- Gloucestershire Hospitals NHS Foundation Trust
- Hereford Hospitals NHS Trust
- Worcestershire Acute Hospitals NHS Trust

Anglia Cancer Network
- Bedford Hospital NHS Trust
- Cambridge University Hospitals NHS Foundation Trust
- Hinchingbrooke Healthcare NHS Trust
- Ipswich Hospital NHS Trust
- James Paget Healthcare NHS Foundation Trust
- Norfolk and Norwich University Hospital NHS Trust
- Peterborough and Stamford Hospitals NHS Foundation Trust
- The Queen Elizabeth Hospital King’s Lynn NHS Trust
- West Suffolk Hospitals NHS Trust

Arden Cancer Network
- George Eliot Hospital NHS Trust
- South Warwickshire General Hospitals NHS Trust
- University Hospitals Coventry and Warwickshire NHS Trust
- Worcestershire Acute Hospitals NHS Trust

Avon, Somerset and Wiltshire Cancer Network
- North Bristol NHS Trust
- Royal United Hospital Bath NHS Trust
- Taunton and Somerset NHS Foundation Trust
- United Bristol Healthcare NHS Trust
- Weston Area Health NHS Trust
- Yeovil District Hospital NHS Foundation Trust
## Executive Summary

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<td><strong>Humber and Yorkshire Coast Cancer Network</strong></td>
<td>Hull and East Yorkshire Hospitals NHS Trust</td>
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<td></td>
<td>Northern Lincolnshire and Goole Hospitals NHS Foundation Trust</td>
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<td></td>
<td>Scarborough and North East Yorkshire Healthcare NHS Trust</td>
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<tr>
<td><strong>Kent and Medway Cancer Network</strong></td>
<td>Dartford and Gravesham NHS Trust</td>
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<td></td>
<td>East Kent Hospitals NHS Trust</td>
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<td>Maidstone and Tunbridge Wells NHS Trust</td>
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## Executive Summary

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- Barnet and Chase Farm Hospitals NHS Trust
- North Middlesex University Hospital NHS Trust
- Royal Free Hampstead NHS Trust
- The Princess Alexandra Hospital NHS Trust
- The Whittington Hospital NHS Trust
- University College London Hospitals NHS Foundation Trust

### North of England Cancer Network
- City Hospitals Sunderland NHS Foundation Trust
- County Durham and Darlington NHS Foundation Trust
- Gateshead Health NHS Foundation Trust
- North Cumbria Acute Hospitals NHS Trust
- Northumbria Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Trust
- South Tyneside NHS Foundation Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust

### North Trent Cancer Network
- Barnsley Hospital NHS Foundation Trust
- Chesterfield Royal Hospital NHS Foundation Trust
- Doncaster and Bassetlaw Hospitals NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- The Rotherham NHS Foundation Trust

### Pan Birmingham Cancer Network
- Heart Of England NHS Foundation Trust
- Sandwell and West Birmingham Hospitals NHS Trust
- University Hospital Birmingham NHS Foundation Trust
- Worcestershire Acute Hospitals NHS Trust

### Peninsula Cancer Network
- Northern Devon Healthcare NHS Trust
- Plymouth Hospitals NHS Trust
- Royal Cornwall Hospitals NHS Trust
- Royal Devon and Exeter NHS Foundation Trust
- South Devon Healthcare NHS Foundation Trust

### South East London Cancer Network
- Bromley Hospitals NHS Trust
- Guy’s and St Thomas’ NHS Foundation Trust
- King’s College Hospital NHS Foundation Trust
- Queen Mary’s Sidcup NHS Trust
- The Lewisham Hospital NHS Trust
# Executive Summary

**South West London Cancer Network**
- Epsom and St Helier University Hospitals NHS Trust
- Kingston Hospital NHS Trust
- Mayday Healthcare NHS Trust
- St George’s Healthcare NHS Trust
- The Royal Marsden NHS Foundation Trust

**Surrey, West Sussex and Hampshire Cancer Network**
- Ashford and St Peter’s Hospitals NHS Trust
- Frimley Park Hospital NHS Foundation Trust
- Royal Surrey County Hospital NHS Trust
- Surrey and Sussex Healthcare NHS Trust

**Sussex Cancer Network**
- Brighton and Sussex University Hospitals NHS Trust
- East Sussex Hospitals NHS Trust
- Worthing and Southlands Hospitals NHS Trust

**Thames Valley Cancer Network**
- Buckinghamshire Hospitals NHS Trust
- Heatherwood and Wexham Park Hospitals NHS Foundation Trust
- Milton Keynes Hospital NHS Foundation Trust
- Oxford Radcliffe Hospitals NHS Trust
- Royal Berkshire NHS Foundation Trust
- Swindon and Marlborough NHS Trust

**West London Cancer Network**
- Ealing Hospital NHS Trust
- Imperial College Healthcare NHS Trust
- North West London Hospitals NHS Trust
- The Hillingdon Hospital NHS Trust
- West Middlesex University Hospital NHS Trust

**Yorkshire Cancer Network**
- Airedale NHS Trust
- Bradford Teaching Hospitals NHS Foundation Trust
- Calderdale and Huddersfield NHS Foundation Trust
- Harrogate and District NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- Mid Yorkshire Hospitals NHS Trust
- York Hospitals NHS Foundation Trust

**North Wales Cancer Network**
- Conwy and Denbighshire NHS Trust
- North East Wales NHS Trust
- North West Wales NHS Trust
### Executive Summary

**South East Wales Cancer Network**
- Cardiff and Vale NHS Trust
- Gwent Healthcare NHS Trust
- North Glamorgan NHS Trust
- Velindre NHS Trust

**South West Wales Cancer Network**
- Bromorgannwg NHS Trust
- Carmarthenshire NHS Trust
- Ceredigion and Mid Wales NHS Trust
- Pembrokeshire and Derwen NHS Trust
- Swansea NHS Trust

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**Figure 1.11 Routes of Submissions by Trust**

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<td>Pembrokeshire and Derwen NHS Trust</td>
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<td>Swansea NHS Trust</td>
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</table>

NB: For Figures 1.10 and 1.11 Cancer Networks listed reflect current configuration. Analyses within the body of the report are based on the configuration during the data collection period.

* Due to an incorrect organisation code being used, data submitted by the East and North Hertfordshire NHS Trust (Mount Vernon Cancer Centre) in the Mount Vernon Cancer Network, is reported under The Hillingdon Hospital NHS Trust (West London Cancer Network)
Background to head and neck cancer and comparative audit

For a broader introduction, please refer to the Second Annual report from which the synopsis below is derived.

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 6,700 new cases diagnosed in England and Wales each year¹²(ICD Codes C0-C14 and C30-C32).

The most common cancer sites are larynx and oral cavity, and more than 90 percent of all malignant tumours in the head and neck are squamous cell carcinomas (SCC) arising from the lining mucosa.

2.1.1 Cancer sites

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

- **oral cavity**: ICD-10 codes C00.3, 4 (mucosa of upper and lower lips) and 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, C32.9 (supraglottis (including lingual surface of epiglottis), glottis and subglottis).

2.1.2 Impact of head and neck cancer on patients

The disease burden of head and neck cancer is significant. Patients require intensive investigation, multimodality 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, smell, breathing and normal social interaction and work capabilities is significant.

Second primaries ³, ⁴ and locoregional recurrence in either the treated field or upper aerodigestive tract, mean that continued long-term surveillance is desirable.

2.1.3 Outcome in head and neck cancer

Cancers of the larynx and oral cavity are associated with significant mortality, for example, 5 year survival for larynx cancer is around 50 per cent.

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-morbidity, late presentation and the high median age of incidence.⁵, ⁶

2.2 Measuring clinical care

Measuring clinical care has proven to be notoriously difficult. Establishing a national baseline is the first step in defining existing care delivery. This is a primary function of this national audit.

The core issue addressed in the first phase of the National Head and Neck Cancer Audit is:

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

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

The limitations of historic sources of head and neck cancer have been previously discussed and the first two reports ⁷, ⁸ act as a national prospective baseline of information.

The DAHNO system 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. 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.
2.3 Key partners and drivers in developing clinical audit

2.3.1 The National Clinical Audit Support Programme (NCASP) and Patient’s Outcomes Programme

Both the National Clinical Audit Support Programme (NCASP) and Patients’ Outcomes Programme, (Healthcare Commission), aim to foster high quality audits in which the clinical direction is provided through the appropriate national professional bodies and where management of the process, including project management and provision of IT, is undertaken by appropriate specialists.

The programmes are designed to support clinicians who wish to audit the quality of their care. The national audits provide benchmarking and comparative information via a quality assured approach applying risk adjustment (eg casemix adjustment) where necessary.

The National Clinical Audit Support Programme (NCASP), within The NHS IC, now manages audits in heart disease, diabetes and cancer. The majority of this work is commissioned directly by the Healthcare Commission.

There are three established national clinical audits in cancer, covering head and neck, lung and bowel cancers and two new audits in oesophago-gastric cancer and in mastectomy and breast reconstruction.

In 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.

The Healthcare Commission has contracted to fund this and the other cancer audits until 2009, but will be succeeded by the new commissioner, the Healthcare Quality Improvement Partnership, for the audits in 2008.

As well as providing feedback so that local clinicians and managers can identify where service improvements need to be made, further spurs to improve patient care may come in several ways:

- national reports summarise the key messages, often receiving considerable media attention when published
- since 2005/2006, information about participation in the projects is being used to cross-check Provider Trusts’ self-assessments against the Core Standards, as part of the Healthcare Commission’s new Annual Health Check
- from 2006/2007, findings from the projects will be used to help cross-check declarations that Provider Trusts make about Developmental Standards.

2.3.2: “NHS Plan” in England 9 and “Designed to tackle cancer” in Wales 10, 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.

2.3.3 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.

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 200511 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 and subsequently developed measures at: www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer.

The areas addressed, include head and neck Cancer Network and MDTs, referral, diagnosis
and assessment, treatment services, post-treatment follow-up and care, prevention and awareness, patient centred care and palliative care. An active process of peer review of compliance with these measures is ongoing across England.

In Wales, national standards for Head and Neck Cancer Services 2005 define the core aspects of the service that should be provided for cancer patients throughout Wales by March 2009. The standards are to be used in conjunction with other requirements for example, the National Institute for Clinical Excellence (NICE) recommendations.
3 DAHNO Application Infrastructure

3.1 The DAHNO System

The DAHNO (Data for Head and Neck Oncology) system which supports the head and neck cancer audit, provides both technical infrastructure for data collection across England as well as facilities for local and central data analysis to deliver continuous comparative audit. Data from Wales is collected within the Cancer Network Information System Cymru (CaNISC) and uploaded to DAHNO.

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 hospital’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 4.

3.1.1 DAHNO Application

The National Head and Neck Cancer Audit application (known as DAHNO - Data for Head and Neck Oncology) 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.

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.

3.1.2 Data submission from Wales

Data from Wales, collected in a summary electronic patient record (CaNISC), is collated and uploaded to the DAHNO application as a CSV file.

3.2 DAHNO application security and patient confidentiality

3.2.1 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 Provider Trusts / Cancer Networks). Several levels of security are built in to 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 user access. 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 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), ensuring both non-repudiation (a user cannot deny that they have accessed data) and that users / organisations only access their own records. Users may be given ‘read only’ or editing rights. Users can delete records with correct permissions and if no child documents relate to that record.

The application is encrypted so if any unauthorised person tried to obtain the hard drive upon which the DAHNO application exists, they would also need an authorised ID file (and password knowledge) to access it. All system database accesses are recorded in a system log file that can be audited in event of suspected security threats or data misuse.
3.2.2 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 (NHS Net) where it is securely stored on a highly encrypted national computer database. 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.
4 Methods and approaches

4.1 Methodology

A generic methodology in common with other National Clinical Audit Support Programme (NCASP) cancer audits was followed and was described in the Second Annual Report

4.2 Clinical aspects

4.2.1 Inclusions and exclusions in the head and neck cancer audit Phase I

The National Head and Neck Cancer Audit aims to identify and include the following details from contributory centres:

- new primary cases of squamous cell head and neck carcinoma involving the larynx and oral cavity

For larynx, this comprises: cancer sites ICD-10 C10.1, C32.0, C32.1, C32.2, C32.8, C32.9 (supraglottis (including lingual surface of epiglottis), glottis and subglottis) and for oral cavity: cancer sites C00.3, 4 (mucosa of upper and lower lips) and C02-C06 (buccal mucosa, upper alveolus and gingiva, lower alveolus and gingiva, hard palate, tongue (lateral, 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))
- decompensation from co-morbidity at diagnosis
- whether management of cancer patients has been by an identified MDT and to agreed standards with equity of care and without undue delay
- the primary treatment modality(ies) received (including adjuvant therapy) for larynx and oral cavity
- disease eradication
- head and neck cancer specific mortality rate and age specific corrected survival.

The 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.

4.3 Determining cancer centres: Provider Trusts managing head and neck cancer

Throughout the current year each Cancer Network has been invited to attend regional training sessions to both encourage the few yet to submit data, as well as to provide training and feedback to contributory individuals, Provider Trusts and Cancer Networks.

In Wales, submission of data is by upload from the CaNISC system, and a list of organisations providing head and neck cancer care in Wales was provided.

4.4 DAHNO improvements rolled out in 2007

A Web-Accessible Interface (WAI) has recently been implemented in the existing DAHNO application following user feedback. The Web-Accessible Interface for DAHNO is currently running in parallel to the Notes-Client Accessible DAHNO (i.e. we have not yet decommissioned the Notes-Client interface) to give users time to switch over (the Web-Accessible Interface, and the Notes-Client Interface are interfaces to the same underlying DAHNO database, so no transfer of data is required when switching from one interface to the other).

The advantages of switching to the Web-Accessible Interface (WAI) for DAHNO are:

1) No more user licences are required - user access is based upon one server licence
2) Nearly all data-entry restrictions have been removed.

3) Users directly access the central DAHNO application, so there is no need for time-consuming communication between the central and local (hospital) database replicas.

4) Because there are no local DAHNO database replicas, the probability of database corruption will be greatly reduced.

The WAI DAHNO application has been designed to accommodate data collection for Phase II of the National Head and Neck Cancer Audit, while NCA DAHNO remains only viable for Phase I data collection. However, a hospital can enter Phase I data using NCA DAHNO, and then switch to WAI DAHNO to compliment that information by entering Phase II data items. However, because of the advantages listed above, users are encouraged to switch from using NCA DAHNO, to WAI DAHNO as soon as they are able.

4.5 Priority outputs and rationale

Refer to Appendix 5.

4.6 Data standards

The audit dataset\textsuperscript{14,15} a subset of the National Cancer Dataset (NCDS) received full operation standard approval from the Information Standards Board (ISB) in May 2006.
5 Benefits of Participation in the Audit. Why is comparative audit in head and neck cancer important?

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\textsuperscript{16} (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 ‘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. A previous audit\textsuperscript{17} by BAHNO\textsuperscript{18} 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 co-morbidity

• 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 of the highest, we would probably be able to improve long-term survival rates without any therapeutic development.

Initially, the National Head and Neck Cancer Audit has focused on adherence to previously determined process standards\textsuperscript{19,20,21}. A group led for BAHNO by Professor Martin Birchall, is currently developing a review of standards applicable to the audit. In time it is intended that the National 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.

Wider benefits to the patient, clinical team and the organisation of participation in the audit are significant in supporting those caring for patients with head and neck cancer improve their services. These improvements in organisation of services and care for patients can only be realised if the service’s current practice is known. This is what this audit aims to do – providing recommendations of good practice in head and neck cancer care, from an expert panel of MDT professionals, measuring practice against those standards and feeding this back to the organisations.

5.1 The Healthcare Commission and Annual Health Check

Participation is used in the Healthcare Commission’s Annual Health Check of NHS Provider Trusts in England, 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.

In Wales, the Healthcare Strategy set out in ‘Designed for Life’\textsuperscript{19} requires that all cancer teams participate in all Wales clinical audit by March 2008.

5.2 England

One of the key commitments of the NHS Cancer Plan\textsuperscript{9} and the subsequent Cancer Reform Strategy\textsuperscript{22} (which applies to England only), 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.

The Cancer Reform Strategy builds on the progress of the Cancer Plan. It recognises the new challenges and opportunities facing cancer, such as rising incidence, advances in medical technologies, new drugs and
Benefits of Participation in the Audit. Why is comparative audit in head and neck cancer important?

rising expectations amongst the public. An element of the strategy is clinical outcomes measurement.

5.3 Wales

One of the key commitments of the Assembly Government is to bring survival rates up to the best in Europe. The Assembly’s policy ‘Designed to Tackle Cancer in Wales’ requires all cancer teams using CaNISC to be participating routinely in national clinical audits and benchmarking with teams in the UK and Europe where possible by March 2008.

5.4 Benefits of participation across the healthcare pathway

5.4.1 For Patients

With ever increasing demand from patients to identify well performing services and high quality clinical care this audit can provide information to both patients and patient advocates to facilitate informed patient choice. Published best practice guidance can be used to improve communication between patient, families and carers with health professionals by providing a rationale for treatment options and what to expect in the care pathway.

“The National Head and Neck Cancer Audit continues to provide a valuable tool for informing both patients and allied health professionals. It is an indicator of centres of clinical performance enabling a better service for patients with head and neck cancer. The DAHNO Team is to be congratulated yet again for their hard work in exploring other avenues and collating even more information for the benefit of both patient and clinician. Well done!”

Christine Piff
Founder and Chief Executive of Let’s Face It

5.4.2 For National monitoring bodies

Healthcare organisations are increasingly scrutinised by external agencies seeking assurance on quality of care delivered. Measures of clinical quality are also likely to be used increasingly in the future to monitor the performance of individual doctors. Whilst mortality and other outcomes have traditionally been used as quality measures, confounding variables may mask significant differences in quality of care and correlation between mortality and clinical quality is often low. Measures of clinical process as found within the National Head and Neck Cancer Audit, have many advantages over outcomes, especially where these are accepted universal components of head and neck care and have a greater potential to reflect team performance. They also have a much shorter audit cycle compared to 5 year survival figures in isolation.

5.4.3 For Commissioners of Services

As for patients, this comparative, continuous, national audit is a tool for commissioners of head and neck cancer services to be assured of the timeliness, quality and performance of local provision. Year on year reporting facilitates benchmarking and adjustment to reflect local differences in disease extent and contributory factors. It can be used to inform investment and development and be used constructively in a dialogue in improving quality of clinical care.

5.4.4 For Clinicians and Clinical Teams

The audit aims to produce a national and local picture of care for patients with head and neck cancer against a number of professionally agreed best practice standards. This baseline measurement and comparator is the starting point in developing and improving clinical practice at a local level. The evidence gained in the audit can be used at both a local and national level as hard evidence for the development of services. The audit is also useful in the education and training of healthcare professionals across the multi-disciplinary team and participation can demonstrate a commitment to quality improvement activities required to meet professional appraisal requirements.
Benefits of Participation in the Audit. Why is comparative audit in head and neck cancer important?

“To have a national database that is of a high standard is mandatory in the modern NHS. It will, with time, not only benefit patients in their outcomes from treatment, but clinicians in delivering evidence based medicine. Due to the low number of cases no one unit / MDT can accumulate enough cases in a short time to get a clear picture of outcome. With the National Head and Neck Cancer audit this is now happening and with full data entry on all cases, this will occur sooner rather than later.

This is starting to alter the way care is delivered even now, and it is answering some of the questions on regional treatment differences within head and neck cancer. With more data a clearer picture will appear resulting in improved patient outcomes. So I appeal to all to contribute and complete all data fields.”

Simon C Hodder FDS, FRCS, Dip FM
Consultant Oral Maxillofacial Head and Neck Surgeon
Chair All Wales Head and Neck Steering Group

The provision of appropriate professional support throughout the patient pathway should be seen as a priority requirement. Expert Panel members realise this has significant resource implications, but their view is also 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, helping to quantify deficit, and its correct capture onto the DAHNO application would identify the national profile of provision.

The accumulated data within DAHNO (now some 5,000 cases) is helping to build a high quality clinical database (HQCD) from consecutive cases which can provide significant research opportunities from anonymised data in the future. This database provides both comprehensive and accurate information, including recording patient details that affect outcome. With sufficient data on confounding variables, answers may be provided to questions comparing treatments that randomised controlled trials will never achieve sufficient power to answer.

5.4.5 For Provider Organisations

As mentioned previously participation is used in the Healthcare Commission’s Annual Health Check of NHS Provider Trusts in England, to support monitoring quality and performance against agreed clinical standards and benchmarks. Participating organisations are given information upon which they can judge the performance of their clinical services and target resources to specific areas requiring improvement. Benchmarking of local services against peer organisation is also enabled with a view to driving up the quality of service provision.

5.5 Realising the benefits

The true benefits are realised when clinical teams, supported by their organisations, read, discuss and act on the findings of national audits.

This third report, which has increased the amount of trust identifiable analysis, is providing organisations with evidence of their clinical performance against the national picture and standards of good practice, augmented by local reports given to trusts submitting more than 10 cases. Using the recommendations made in this report, a Local Action Planning toolkit will be issued to all organisations to help facilitate change in practice (where this is required).
Improvements and Recommendations

6 Improvements and Recommendations

Having collected data for 3 years, it is now possible to track improvements over time and to identify areas of practice which still require further attention.

6.1 Improvements

6.1.1 Case ascertainment

Over the life of the audit it is clear to see that there has been a significant increase in the number of cases entered into the audit. This is a result of more trusts participating and existing organisations improving their processes for capturing patients.

6.1.2 Data quality

Data quality has improved significantly over the last year with the average for all trusts increasing from 80 to 139. This calculation was not available in 2005. How the calculation is derived can be found in Appendix 8.

Developments, in both processes at trust level and within the administration of the audit at national level, have resulted in improvements in the overall quality of the data submitted. However, the number of cases where key data is not recorded is still unacceptably high.

Good Practice Standard

All trusts providing head and neck cancer care, whether diagnosing and/or treating should submit data to the National Head and Neck Cancer Audit.

Good Practice Standard

All trusts providing head and neck cancer care, whether diagnosing and/or treating should submit comprehensive and complete data to the National Head and Neck Cancer Audit.

Good Practice Example

There are a number of different approaches across the country in how trusts ensure maximum case submission. At The Newcastle Upon Tyne Hospitals NHS Foundation Trust, the MDT coordinator captures details of all patients attending the MDT onto a proforma and then enters them into DAHNO. A mid-year local audit is used to check those patients entered onto DAHNO with diagnosed patients entered into the pathology system. This results in a high case ascertainment figure for the trust.

Close collaboration between data in-putter and clinical team has been identified as key to achieving high quality data in DAHNO. At the Royal Devon and Exeter NHS Foundation Trust, data quality is achieved in staging from having the data coordinator work closely with the clinician, this improves the knowledge base of the coordinator and a process is established to ensure good quality data in the system.
Improvements and Recommendations

6.1.2.1 Co-morbidity

Recording of co-morbidity has risen steadily over the last three years from 18 per cent to 30 per cent, but this is still unacceptably low when the recording of this is so important.

Severity of co-morbidity is associated with survival, selection of initial treatment and the assessment of the quality of care given. In many cases co-morbidity may be more important than tumour site, or TNM staging, in determining the patient’s prognosis. It is particularly important in slow growing cancers and those affecting older people such as oral cavity, pharynx and larynx.

The derivation of a co-morbidity score can achieved with minimum resource by use of a patient self completion questionnaire. A score derivation chart can be found in Appendix 8 and the questionnaire at www.ic.nhs/canceraudits.

Good Practice Example

At The Newcastle Upon Tyne Hospitals NHS Foundation Trust, the MDT meeting is the focal point for collecting data for the audit, including co-morbidity. An enthusiastic lead clinician ensures all staff are familiar with the requirements of co-morbidity collation and works closely with other clinical colleagues and administrative staff to record this aspect of care.

6.1.3 Number of patients seen at MDT

Of the total cases submitted, the number of patients recorded as seen at the MDT has gradually risen to 74 per cent in 2007 from 68 per cent in 2005, which is encouraging for such an important element of care. Though there is still room for more improvement.

Effective MDT working is critical for treatment planning. All patients should be discussed. Effective coordination of MDT meetings helps to ensure that:

- All relevant information is available
- Decisions are recorded and communicated to all relevant parties
- Waiting times are monitored proactively
- Further steps are planned, booked and coordinated.

Good Practice Standard

Patient expectations are that all care discussions are being made at a MDT, and head and neck cancer teams need to provide assurance around this important aspect of care.
Good Practice Example
At Northampton General Hospital NHS Trust excellent MDT attendance is achieved through having an effective process linking the histopathology system into the MDT, by producing a list of all newly diagnosed patients as the agenda for the meeting. This ensures that no patient is missed off the MDT list. A similar approach is also made at The Royal Wolverhampton Hospitals NHS Trust.

Good Practice Example
At Mid Yorkshire NHS Trust the patient pathway coordinator is key to ensuring all patients are seen at the MDT and that the appropriate documentation is available. They also have a MDT alert system for patients referred to Leeds for treatment. As a result of these systems and processes this trust has achieved a high level of patients being seen at the MDT.
## Improvements and Recommendations

### Figure 6.2 Issues and recommendations

**KEY RECOMMENDATIONS – high priority in red text**

<table>
<thead>
<tr>
<th>Issues</th>
<th>Recommendations (high priority in blue text)</th>
<th>Group to action</th>
</tr>
</thead>
</table>
| 6.2.1 Developing a local response to the audit findings | • Each trust should develop an action plan based on the findings in the audit.  
  • An action planning tool will be released to coincide with production of local reports in summer 2008  
  • Networks should facilitate comprehensive introduction of the action planning tool  
  • A local analysis tool has been commissioned by NCASP and will be available in autumn 2008 to support local analysis of a selection of outputs | N T U M |
| 6.2.2 Developing a network response to the audit findings | • Each network should liaise with provider trusts to support a comprehensive audit process in head and neck cancer  
  • The network should encourage head and neck tumour site specific groups to regularly discuss comparative audit on their agendas and provider trusts to provide an appropriate infrastructure  
  • Networks should reflect on where variation in access occurs within the network as identified in trust identifiable data and seek to examine pathways that underpin it | N T M |
### Improvements and Recommendations

#### 6.2.3 Clinical issues for multi-disciplinary teams

A number of issues have been highlighted in the report. The Expert Panel had concerns about the care delivered, based on the data submitted. This may reflect the absence of collection rather than true practice. However, the teams should assess their local delivery against the items opposite.

<table>
<thead>
<tr>
<th>Issues</th>
<th>Recommendations (high priority in blue text)</th>
<th>Group to action</th>
</tr>
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<tbody>
<tr>
<td>MDTs should:</td>
<td>Ensure the timeliness of pathways to meet national access targets</td>
<td>N T M U</td>
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<tr>
<td>MDTs should:</td>
<td>Ensure the awareness and involvement of general dental practitioners and community dental services in urgent cancer referral processes</td>
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<tr>
<td>MDTs should:</td>
<td>Ensure that speech and language therapists and dieticians have active involvement in patient management and their care pathways (see below re Phase II)</td>
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<tr>
<td>MDTs should:</td>
<td>Ensure that tumour staging (TNM) is confirmed and recorded prior to care planning and following surgical procedures</td>
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<td>MDTs should:</td>
<td>Ensure that good dental health is maintained throughout treatment</td>
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<td>MDTs should:</td>
<td>Ensure provision of surgical voice restoration counselling, pre-treatment, for all patients having a laryngectomy</td>
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<tr>
<td>MDTs should:</td>
<td>Ensure provision of swallowing counselling, pre-treatment, for all patients who are about to undergo oral and oropharyngeal resective and or reconstructive surgery with free tissue transfer or partial laryngo-pharyngeal surgery</td>
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<tr>
<td>MDTs should:</td>
<td>Should ensure that delays in commencement of radiotherapy/chemotherapy – either as primary or adjunctive treatment – are minimised</td>
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<td>MDTs should:</td>
<td>Ensure the recording of all treatments by identifying and documenting any reasons for the provision of chemotherapy in isolation as first line treatment, and where it is used as part of a chemo-radiation regime.</td>
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<tr>
<td>MDTs should:</td>
<td>Facilitate meeting patient expectations that all care discussions are being made at a MDT, and head and neck cancer teams need to provide assurance around this important aspect of care delivery. This is unanimously supported by the expert panels.</td>
<td></td>
</tr>
<tr>
<td>MDTs should:</td>
<td>Each MDT should review on a case by case basis as to why decisions are made outside of the MDT, and put steps in place to ensure all cases are discussed</td>
<td></td>
</tr>
<tr>
<td>MDTs should:</td>
<td>Teams should confirm that chest imaging has occurred in all head and neck cancer patients prior to planning treatment as synchronous malignancies of the chest can occur and have a significant impact on treatment options.</td>
<td></td>
</tr>
<tr>
<td>MDTs should:</td>
<td>For accurate understanding of care pathways it is important that all components of a surgical procedure are recorded to provide a true reflection of the breadth and complexity of surgical management.</td>
<td></td>
</tr>
<tr>
<td>MDTs should:</td>
<td>A general theme of the analysis is that the second phase of treatment is not being well captured. This may reflect MDT data capture processes. Teams are encouraged to capture all parts of the patients’ careplan.</td>
<td></td>
</tr>
</tbody>
</table>

#### 6.2.4 Standards in clinical care

Professional bodies, led by the British Association of Head and Neck Oncologists (BAHNO) and facilitated by the National Head and Neck Cancer Audit team, are evolving clinical standards.

Support and comply with evolving clinical standards as they become available in 2008.
### Improvements and Recommendations

<table>
<thead>
<tr>
<th>Issues</th>
<th>Recommendations (high priority in blue text)</th>
<th>Group to action</th>
</tr>
</thead>
</table>
| **6.2.5 Data quality and completeness**                                | - Each provider trust should seek to provide assurance on the quality and timeliness of care delivered to head and neck cancer patients by comprehensive and continuous contribution to the audit.  
- The head and neck cancer audit team will continue to expand the volume of trust identifiable data reported as data becomes more robust.  
To provide risk adjustment requires high levels and data quality and completeness. During audit rollout assumptions have been made that poor or missing data did not necessarily represent actual treatment given. Now that the audit is established this assumption is inappropriate and poor or missing data will be reflected as the treatment given:  
- Networks should increase local awareness and encourage compliance with the audit  
- Provider 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.  
Users should familiarise themselves with all the items detailed within the audit, and use opportunities to attend DAHNO workshops. The influence of factors such as co-morbidity and performance status can have a significant effect upon treatment outcomes. Therefore all MDTs should collect these data set items.  
All Cancer Networks and constituent Provider 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.ic.nhs.uk/canceraudits  
All MDTs should seek to accurately capture resective pathology information including pathological stage for every patient undergoing surgical treatment. This will enable true stage comparison of outcomes.                                                                                                                                                                                                                     | T M D U D N T U P |
| Absence of submission completeness on key fields eg certainty factor, performance status and co-morbidity. |                                                                                                                                                                                                                                                                                                                                                                                                         |                 |
| 67 per cent of potential records submitted. Two Cancer Networks have no submissions to this second annual report. |                                                                                                                                                                                                                                                                                                                                                                                                         |                 |
| Absence of resective pathology information in submissions.             |                                                                                                                                                                                                                                                                                                                                                                                                         |                 |
| **6.2.6 Data process issues**                                          | - All networks will be regularly contacted by the Head and Neck cancer audit team to confirm contacts at Provider Trusts/hospitals that deliver head and neck cancer care.  
Organisations should review the data collection process and ensure that it extends across the whole pathway.                                                                                                                                                                                                                                                                                  | D N U T N T U |
## Improvements and Recommendations

<table>
<thead>
<tr>
<th>Issues</th>
<th>Recommendations (high priority in blue text)</th>
<th>Group to action</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>6.2.7 Application issues-web DAHNO and Phase II</strong>&lt;br&gt;Launch of web DAHNO.</td>
<td>A web based access to DAHNO has been introduced (January 2008) in response to user requests for a more user friendly environment. Details on this and registration requirements can be found at <a href="http://www.ic.nhs.uk/canceraudits">www.ic.nhs.uk/canceraudits</a>&lt;br&gt;The web version contains all the required fields for Phase II.</td>
<td>D U</td>
</tr>
<tr>
<td>Uploading from third party systems.</td>
<td>The head and neck cancer audit team continue to advise IT providers of requirements to achieve successful upload. Provider trusts uploading information should perform this on a regular basis throughout the index year. Provider trusts uploading information via csv should commence preparation of csv requirements to meet Phase II as well as attending future workshops.</td>
<td>D T D U</td>
</tr>
<tr>
<td>Reporting of import errors.</td>
<td>The head and neck cancer audit team to proactively advise users via central import log of issues with import.</td>
<td></td>
</tr>
<tr>
<td><strong>6.2.8 Audit data to support clinical process</strong>&lt;br&gt;Contemporaneous data collection</td>
<td>Although DAHNO is an audit process the timely collection of patient pathway data can support and expedite the overall delivery of patient care.</td>
<td>N T U</td>
</tr>
</tbody>
</table>
7 Statistical methods used for data analysis

The presented information is an analysis of a sample of larynx cancer and oral cancer cases from hospital Provider Trusts across England and Wales. Most of the reported measures are either a count of cases or a percentage of total recorded cases. Notes accompanying each measure seek to make the basis of the calculations clear. The interpretation of the results must take into consideration the incomplete ascertainment of the cohort; not all incident cases in England and Wales have been entered onto the system, and many of those cases that are recorded have data items which have not been entered.

- Counts are the totals 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 recorded value.

- The calculation of percentages involves a count and a denominator. The choice of denominator is complicated by incompleteness. For certain measures the selected denominator is the total number of registrations, for others it has been more appropriate to use the number of registrations with any recorded value for a particular data item.

The quality of any data analysis is dependent upon the ascertainment, completeness and accuracy of the data submitted. Analysis is based purely on the data submitted to the DAHNO application by contributing Provider Trusts. It is important to recognise that because some records are incomplete, the published information is based on fewer than the total number of registered cases. Particularly vulnerable are the interval calculations, for instance, the interval from referral to first appointment, broken down by two week wait referrals and others (as in section 8.5.4); if a record has either of the two dates or referral details missing, that record cannot contribute to the chart.

Data is presented as a simple description of data gathered during work-in-progress. As the quality and quantity 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).

Analysis was carried out using Stata® 8.1, Microsoft® Access 2000 and Microsoft® Excel 2000.
8 Findings

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 version 0.2 November 2007, supplied to the Cancer Registries by the National Head and Neck Cancer Audit Project Team. Further analyses were performed at the request of the Expert Panels. The data extract period includes patient records with a ‘date of diagnosis’ between 1 November 2006 and 31 October 2007 inclusive.

8.2 Analysed data

Over 2,100 patient diagnoses have been included in the analysis. This has increased by approximately 50 per cent from the first National Head and Neck Cancer Audit Annual Report and 40 per cent from the second annual report. Data has again been included from Wales.

<table>
<thead>
<tr>
<th>Figure 8.2.a: Submitted diagnoses by year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Diagnoses submitted</strong></td>
</tr>
<tr>
<td>04-05</td>
</tr>
<tr>
<td>1,042</td>
</tr>
<tr>
<td>05-06</td>
</tr>
<tr>
<td>1,446</td>
</tr>
<tr>
<td>06-07</td>
</tr>
<tr>
<td>2,130</td>
</tr>
<tr>
<td><strong>Submissions from</strong></td>
</tr>
<tr>
<td>England only</td>
</tr>
<tr>
<td>England and Wales</td>
</tr>
<tr>
<td>England and Wales</td>
</tr>
<tr>
<td><strong>Months of audit</strong></td>
</tr>
<tr>
<td>21</td>
</tr>
<tr>
<td>13</td>
</tr>
<tr>
<td>12</td>
</tr>
<tr>
<td><strong>Estimate for period of audit</strong></td>
</tr>
<tr>
<td>4,454</td>
</tr>
<tr>
<td>2,945</td>
</tr>
<tr>
<td>3,032</td>
</tr>
<tr>
<td><strong>Corrected annual estimate</strong></td>
</tr>
<tr>
<td>2,545( England only)</td>
</tr>
<tr>
<td>2,718</td>
</tr>
<tr>
<td>3,032</td>
</tr>
<tr>
<td><strong>Percent of estimate</strong></td>
</tr>
<tr>
<td>23%</td>
</tr>
<tr>
<td>49%</td>
</tr>
<tr>
<td>67%</td>
</tr>
<tr>
<td><strong>Larynx cancer</strong></td>
</tr>
<tr>
<td>561</td>
</tr>
<tr>
<td>745</td>
</tr>
<tr>
<td>1,049</td>
</tr>
<tr>
<td><strong>Oral cavity cancer</strong></td>
</tr>
<tr>
<td>477</td>
</tr>
<tr>
<td>698</td>
</tr>
<tr>
<td>986</td>
</tr>
</tbody>
</table>

If all estimated cases had been collected, the total would have exceeded 3,000. The estimated figures have risen year on year (a correction factor to the estimation in the first annual report has been included) to reflect the overall rise in cancer incidence. The information presented in this report is, therefore, a snapshot of the total population. The following chart shows an overview of data collected for larynx and oral cavity cancer for cases with data of diagnosis between 1 November 2006 and 31 October 2007.

<table>
<thead>
<tr>
<th>Figure 8.2.b: Analysed Data</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Estimated cases</strong></td>
</tr>
<tr>
<td>3,032</td>
</tr>
<tr>
<td>2,820 England</td>
</tr>
<tr>
<td>212 Wales</td>
</tr>
<tr>
<td><strong>Cases submitted to the DAHNO</strong></td>
</tr>
<tr>
<td>2,130 (67 per cent of estimate)</td>
</tr>
<tr>
<td><strong>Valid registered cases</strong></td>
</tr>
<tr>
<td>2,035</td>
</tr>
<tr>
<td>1,882 England</td>
</tr>
<tr>
<td>153 Wales</td>
</tr>
<tr>
<td><strong>Inconsistent diagnosis data</strong></td>
</tr>
<tr>
<td>95</td>
</tr>
<tr>
<td>(not used for analysis)</td>
</tr>
<tr>
<td><strong>Larynx cases</strong></td>
</tr>
<tr>
<td>1,049 (58 per cent)</td>
</tr>
<tr>
<td><strong>Oral cavity cases</strong></td>
</tr>
<tr>
<td>986 (76 per cent)</td>
</tr>
<tr>
<td><strong>Cases with 1 tumour</strong></td>
</tr>
<tr>
<td>1,045</td>
</tr>
<tr>
<td><strong>Cases with 2 tumours</strong></td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td><strong>Cases with 1 tumours</strong></td>
</tr>
<tr>
<td>960</td>
</tr>
<tr>
<td><strong>Cases with 2 tumours</strong></td>
</tr>
<tr>
<td>11</td>
</tr>
<tr>
<td><strong>Cases with 4+ tumours</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>
Findings

A considerable improvement in case ascertainment has occurred with 67 per cent of estimated incident cases being recorded within the database, compared with 49 per cent in 2005-2006. Comprehensive case ascertainment remains a goal for future iterations of the audit to ensure a representative reflection of current English and Welsh head and neck cancer management.

95 diagnoses were excluded from the analysis because of inconsistent diagnosis data, 40 had non larynx or oral cavity site codes, 1 was an unresolved case of site of diagnosis and 54 duplicates were removed.

Of the 1,047 patients with larynx cancer, 1,045 had a single tumour and 2 had two tumours in the index year.

Of the 986 patients with oral cavity cancer, 960 had a single tumour in the index year, 11 patients had two tumours and a single patient had four tumours.

As this is a continuous audit with annual reporting years, inevitably some patients will complete the treatment phase of their pathway beyond the reporting year. 58 patients with a date of diagnosis prior to 1 November 2006, subsequently had treatment and the types of first definitive treatment administered are described below:-

8.3 Where head and neck cancer care happens

2,035 cases were presented for analysis, with a date of diagnosis between 1 November 2006 and 31 October 2007. These comprised 1,049 (51.5 per cent) laryngeal cancers and 986 (48.5 per cent) oral cavity cancers. A breakdown of registrations by anatomic sub-site is included in Figure 8.3.1a.

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

A review of new diagnoses with a diagnosis date prior to 1 November 2006, submitted after the close of the index year for the second annual report, shows that contributors have added a further 394 cases (182 larynx and 212 oral cavity cancers). Future reports will seek to look cumulatively beyond the reporting year. Users are encouraged to provide both diagnostic and treatment data as close as possible to the point of care delivery.
In larynx, as expected, glottic cancers predominate, (52 per cent), with 25 per cent occurring in the supraglottis. This was a similar distribution to that seen previously. ‘Larynx NOS’ (not otherwise specified) represents those cancers which involve cartilage, multiple sub-sites, and are also referred to as transglottic tumours, or it reflects failure to delineate the site of tumour origin.

The number of subglottic tumours previously, in 2005-2006, appeared higher than expected (2.7 per cent compared to 1.7 per cent of all ONS registrations) but was thought likely to reflect a sampling bias. The finding this year of 1.8 per cent is more directly comparable to the ONS expected figure.

In oral cavity, tumours of the lateral border of the tongue are the most common cancer site, (24 per cent), with a more even distribution amongst the remaining sub-sites. The hard palate (7 per cent compared to 2 per cent of all ONS registrations) appears to be, again, over represented as in 2005-2006. The expert panels reflected that this figure may be increased by difficulties in determining the boundary between hard and soft palate and the alveolar process. The inclusion of oropharynx in the 2007-2008 collection year will help define this further. 4 records included in ‘unspecified oral cavity’ have no specific cancer site code record. This was less than that seen previously.
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 and Wales. The estimate of new head and neck primaries of the larynx and oral cavity for England were taken from the CIS for the diagnosis year 2004. The estimates by Cancer Network in England were adjusted by the overall percentage increase in England as a whole, compared with the previous estimates for Cancer Networks in England from the first and second report. The corresponding figure for Wales (and Cancer Networks) was taken from the Welsh Cancer Intelligence and Surveillance Unit for the diagnosis year 2004.

The estimate consists of 2,820 cases in England, comprises 1,691 larynx cancers and 1,129 oral cavity cancers. In Wales, there were 209 cases, of which 114 cases were larynx and 95 cases were oral cavity.

Cancer registry data provides a good estimate of new cases, which allows for incident cases not attending at hospital. It includes a wider selection of tumour sites than oral cavity and larynx. The ONS all registrations data was used to calculate the proportion of all head and neck cancers that are categorised as oral cavity or larynx. Although Cancer Networks serve a geographically defined population, they may also see cross border referrals.
**Findings**

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

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>DAHNO registrations</th>
<th>Estimate for 12 months</th>
<th>DAHNO registrations as % of estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yorkshire Cancer Network</td>
<td>201</td>
<td>145</td>
<td>139</td>
</tr>
<tr>
<td>Northern Cancer Network</td>
<td>147</td>
<td>144</td>
<td>102</td>
</tr>
<tr>
<td>Pan Birmingham Cancer Network</td>
<td>135</td>
<td>112</td>
<td>121</td>
</tr>
<tr>
<td>Peninsula Cancer Network</td>
<td>127</td>
<td>106</td>
<td>120</td>
</tr>
<tr>
<td>Mid Trent Cancer Network</td>
<td>112</td>
<td>95</td>
<td>118</td>
</tr>
<tr>
<td>Cancer Care Alliance of Teesside, South Durham and North Yorkshire</td>
<td>96</td>
<td>59</td>
<td>162</td>
</tr>
<tr>
<td>Leicestershire, Northamptonshire and Rutland Cancer Network</td>
<td>89</td>
<td>71</td>
<td>125</td>
</tr>
<tr>
<td>Merseyside and Cheshire Cancer Network</td>
<td>80</td>
<td>146</td>
<td>55</td>
</tr>
<tr>
<td>Avon, Somerset and Wiltshire Cancer Network</td>
<td>78</td>
<td>99</td>
<td>79</td>
</tr>
<tr>
<td>Derby/Burton Cancer Network</td>
<td>67</td>
<td>39</td>
<td>172</td>
</tr>
<tr>
<td>North Trent Cancer Network</td>
<td>63</td>
<td>96</td>
<td>66</td>
</tr>
<tr>
<td>Greater Midlands Cancer Network</td>
<td>59</td>
<td>107</td>
<td>55</td>
</tr>
<tr>
<td>Sussex Cancer Network</td>
<td>56</td>
<td>56</td>
<td>100</td>
</tr>
<tr>
<td>Three Counties Cancer Network</td>
<td>48</td>
<td>58</td>
<td>83</td>
</tr>
<tr>
<td>Dorset Cancer Network</td>
<td>48</td>
<td>47</td>
<td>102</td>
</tr>
<tr>
<td>Arden Cancer Network</td>
<td>47</td>
<td>47</td>
<td>100</td>
</tr>
<tr>
<td>Humber and Yorkshire Coast Cancer Network</td>
<td>47</td>
<td>58</td>
<td>81</td>
</tr>
<tr>
<td>West Anglia Cancer Network</td>
<td>45</td>
<td>85</td>
<td>53</td>
</tr>
<tr>
<td>Norfolk and Waveney Cancer Network</td>
<td>44</td>
<td>40</td>
<td>110</td>
</tr>
<tr>
<td>Thames Valley Cancer Network</td>
<td>43</td>
<td>113</td>
<td>38</td>
</tr>
<tr>
<td>Mid Anglia Cancer Network</td>
<td>34</td>
<td>47</td>
<td>73</td>
</tr>
<tr>
<td>South Essex Cancer Network</td>
<td>30</td>
<td>31</td>
<td>96</td>
</tr>
<tr>
<td>Greater Manchester and Cheshire Cancer Network</td>
<td>27</td>
<td>208</td>
<td>13</td>
</tr>
<tr>
<td>Mount Vernon Cancer Network</td>
<td>26</td>
<td>51</td>
<td>51</td>
</tr>
<tr>
<td>Kent and Medway Cancer Network</td>
<td>24</td>
<td>96</td>
<td>25</td>
</tr>
<tr>
<td>Surrey, West Sussex and Hampshire Cancer Network</td>
<td>23</td>
<td>52</td>
<td>44</td>
</tr>
<tr>
<td>West London Cancer Network</td>
<td>22</td>
<td>85</td>
<td>26</td>
</tr>
<tr>
<td>Lancashire and South Cumbria Cancer Network</td>
<td>20</td>
<td>104</td>
<td>19</td>
</tr>
<tr>
<td>North East London Cancer Network</td>
<td>20</td>
<td>60</td>
<td>33</td>
</tr>
<tr>
<td>South West London Cancer Network</td>
<td>14</td>
<td>87</td>
<td>16</td>
</tr>
<tr>
<td>Central South Coast Cancer Network</td>
<td>10</td>
<td>123</td>
<td>8</td>
</tr>
<tr>
<td>North London Cancer Network</td>
<td>0</td>
<td>77</td>
<td>0</td>
</tr>
<tr>
<td>South East London Cancer Network</td>
<td>0</td>
<td>76</td>
<td>0</td>
</tr>
<tr>
<td><strong>ENGLAND</strong></td>
<td><strong>1,882</strong></td>
<td><strong>2,820</strong></td>
<td><strong>67</strong></td>
</tr>
<tr>
<td>North Wales</td>
<td>26</td>
<td>46</td>
<td>57</td>
</tr>
<tr>
<td>South West Wales</td>
<td>43</td>
<td>67</td>
<td>64</td>
</tr>
<tr>
<td>South East Wales</td>
<td>84</td>
<td>96</td>
<td>88</td>
</tr>
<tr>
<td><strong>WALES</strong></td>
<td><strong>153</strong></td>
<td><strong>209</strong></td>
<td><strong>73</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>2,035</strong></td>
<td><strong>3,032</strong></td>
<td><strong>67</strong></td>
</tr>
</tbody>
</table>

Networks are shown as defined at the start of the index period November 2006.

*Figure for Wales taken as total larynx and oral cavity registrations from Welsh Cancer Intelligence and Surveillance Unit for 2004.*

*Figure for England taken as total larynx and oral cavity registrations from CIS for 2004.*

*Figures for English Cancer Networks use previous report figures and adjusted by the percentage increase for England as a whole for each network.*
8.3.3 Submission by Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period

Figure 8.3.3.a: Submission by Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period.

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>Submitting Provider Trust to DAHNO</th>
<th>Larynx</th>
<th>Oral Cavity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Counties</td>
<td>Gloucestershire Hospitals NHS Foundation Trust</td>
<td>17</td>
<td>23</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Hereford Hospitals NHS Trust</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Worcestershire Acute Hospitals NHS Trust</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>20</td>
<td>28</td>
<td>48</td>
</tr>
<tr>
<td>Arden</td>
<td>South Warwickshire General Hospitals NHS Trust</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>University Hospitals Coventry and Warwickshire NHS Trust</td>
<td>23</td>
<td>24</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>Worcestershire Acute Hospitals NHS Trust</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>23</td>
<td>24</td>
<td>47</td>
</tr>
<tr>
<td>Avon Somerset and Wiltshire</td>
<td>North Bristol NHS Trust</td>
<td>45</td>
<td>13</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td>Royal United Hospital Bath NHS Trust</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Taunton and Somerset NHS Foundation Trust</td>
<td>11</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>57</td>
<td>21</td>
<td>78</td>
</tr>
<tr>
<td>Central South Coast</td>
<td>Isle of Wight Healthcare NHS Trust</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Basingstoke and North Hampshire NHS Foundation Trust</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
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<td>1,049</td>
<td>986</td>
<td>2,035</td>
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</table>

* Treating Trust only – data are allocated to location entering demographic data, usually diagnosing Trust

**Networks are shown as defined at the start of the index period November 2006.**

The following have merged during the period of this audit: Northern and the Cancer Care Alliance Cancer Networks have merged to become the North of England Cancer Network, Mid Anglia, Norfolk and Waveney, and South Essex Cancer Networks are now Anglia Cancer Network and Essex Cancer Network.

- 2,035 cancers, of a theoretical maximum total of 3,032 cancers have been registered (67 per cent) to the audit.
- 34 out of 36 Cancer Networks in England and Wales have entered at least one patient into the DAHNO system. The minimum contribution from any submitting network was 7 cases.
- No submissions were received from the North London Cancer Network and South East London Cancer Network.
### Findings

**Figure 8.3.3.b: Submission by Cancer Network where over 90 per cent of estimated new head and neck primaries of the larynx and oral cavity in the index period, were made in 2005-2006 and 2006-2007.**

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>Over 90% of estimate in 2005-2006 DAHNO registrations</th>
<th>Over 90% of estimate in 2006-2007 DAHNO registrations</th>
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<td>Leicestershire, Northamptonshire and Rutland Cancer Network</td>
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<td>118</td>
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<td>Pan Birmingham Cancer Network</td>
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<td>Northern Cancer Network</td>
<td></td>
<td>100</td>
</tr>
<tr>
<td>Sussex Cancer Network</td>
<td></td>
<td>96</td>
</tr>
</tbody>
</table>

- 25 networks achieved more than 50 per cent of expected cases and 13 achieved more than 90 per cent compared to 7 out of 34 in 2005-2006.
- At individual Provider Trust level 4 organisations who had previously contributed high levels of registration were unable to achieve this in 2006-2007. These were:
  - Lancashire Teaching Hospitals NHS Trust
  - Salford Royal Hospitals NHS Trust
  - Pennine Acute Hospitals NHS Trust
  - South Warwickshire General Hospitals NHS Trust

For some this was due to a loss of data entry resource and others technical reasons in, for example, the upload of information from third party systems.

- The DAHNO application can receive data by either direct data entry (2/3 of submissions) or by the use of a CSV upload facility (1/3 of submissions). 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. The audit development team continue to try and simplify the upload process.

- Data from Wales was initially collected in the National Summary Electronic Cancer Patient Report (CaNiSic) system and uploaded via a CSV export into DAHNO.

- 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 Provider Trusts in data collection personnel.

- The MDT meeting is a key focal point for data collection as the correct members of the team are assembled.

**8.3.4 Submission by Cancer Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period, where cases had pre treatment recorded T and N staging category**

Counts and percentage of cases with recorded pre treatment T and N staging by provider trust. Trusts have been colour banded to represent completeness of staging information:

- of 2,035 patients, who have been registered to the audit, 1,550 (76.2 per cent) contained T and N pre treatment staging category information

- this year there has been an improvement in staging and organisations are to be encouraged to improve this further
Findings

Figure 8.3.4a: Submitted diagnoses by year where T and N recorded

<table>
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<tr>
<th></th>
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<td>Diagnoses submitted</td>
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<td>1,443</td>
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<td>England and Wales</td>
<td>England and Wales</td>
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<tr>
<td>Cases with T and N staging recorded</td>
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<td>776</td>
<td>1,550</td>
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<tr>
<td>Percent of staging</td>
<td>64.8</td>
<td>53.8</td>
<td>76.2</td>
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</table>

- there is a variation between and within Cancer Networks and between England (79.2 per cent) and Wales (39.2 per cent) in the quantity of staging information submitted.

Good Practice Standard

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 per cent of cases staged in any high quality database collection, to allow valid comparisons to be made.

Figure 8.3.4.b: Submission by Cancer Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period, where cases had recorded T and N staging category.

Key: Green = 75 per cent or more T and N recorded  
Amber = 25 per cent to 75 per cent T and N recorded  
Red = Less than 25 per cent T and N recorded

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>Submitting Provider Trust to DAHNO</th>
<th>Cases submitted where T and N recorded</th>
<th>Total</th>
<th>Percentage of those with T and N recorded</th>
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</thead>
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### Findings

#### Key:
- **Green** = 75 per cent or more T and N recorded
- **Amber** = 25 per cent to 75 per cent T and N recorded
- **Red** = Less than 25 per cent T and N recorded

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>Submitting Provider Trust to DAHNO</th>
<th>Cases submitted where T and N recorded</th>
<th>Total</th>
<th>Percentage of those with T and N recorded</th>
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| Total                          | 119                        | 135                        | 88.1       |                                          |
### Findings

#### Cancer Network

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Findings

Key: Green = 75 per cent or more T and N recorded, Amber = 25 per cent to 75 per cent T and N recorded, Red = Less than 25 per cent T and N recorded

<table>
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<tr>
<th>Cancer Network</th>
<th>Submitting Provider Trust to DAHNO</th>
<th>Cases submitted where T and N recorded</th>
<th>Total</th>
<th>Percentage of those with T and N recorded</th>
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<td></td>
<td>Ceredigion and Mid Wales NHS Trust</td>
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<td>2,035</td>
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- Where trusts only contribute to the diagnostic part of the pathway, final pre-treatment staging may only be confirmed at the MDT led by the treatment centre. Technical difficulties may hinder the reconciliation of data from different sources in some cancer Cancer Networks

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

8.4.1 Age and sex distributions of registrations

Larynx

Figure 8.4.1.a: Larynx Cancer; Registration counts by age and sex.

There were 7 cases with unknown sex;
- 1 case aged 30-34 years
- 4 cases aged 60-64 years
- 1 case aged 65-69 years
- 1 case aged 75-59 years.

There was also one male case with a diagnosis date preceding his birth date.
- 82 per cent of larynx cancer patients were male.
- 7.8 per cent were under 50 years of age.
- The median ages were; for males 67 years and females 64 years.
Findings

- 7 per cent of male cases were under the age of 50. 25 per cent were aged over 75.
- 10 per cent of female cases were under the age of 50. 23 per cent were aged over 75.
- 3 cases (all female) were under the age of 30. Of these (one case was aged between 0-4 years (which was subsequently confirmed as a data entry error) and the other two cases were aged between 20-24 years).
- National Head and Neck Cancer Audit registrations are broadly in line with ONS which reports the rate of laryngeal cancer peaking in the 75 to 79 age group for both males and females.

![Figure 8.4.1.b: Ratio of male to female registrations larynx cancer compared with ratio of males to females in England and Wales.](image)

- The ratio of male to female laryngeal cancers exceeds the ratio of males to females in England and Wales by a factor of approximately 4 beyond the age of 45 years.
- The risk of laryngeal cancer is approximately 4 times greater in males than in females over 45 years of age.
Larynx Cancer Registration Counts by age and sex January 2004-October 2006

Figure 8.4.1.c: Larynx Cancer Registration Counts by age and sex January 2004-October 2007 (2,619 cases).

- Cumulative data of over 2,600 male and female cases from the inception of the audit shows similar distributions by age band supporting the findings above and again confirming contribution from a homogenous population.

- A sub analysis showed no significant difference in age distribution between England and Wales.

- A peak of incidence of laryngeal cancers occurs between the ages of 55 and 79, and future proposals in relation to screening (as proposed in the Cancer Reform Strategy) if applied to larynx cancer would gain greatest return within these age groupings.
Oral Cavity

There were two cases aged less than 20 years of age (one male case aged 15-19 years and one female case aged 0-4 years). (Subsequent enquiry confirmed as an error in data submission with the latter patient being 78 years of age).

Three male cases could not be given an age due to two cases having the diagnosis date preceding the birth date and one case with a missing diagnosis date.

Sex was recorded as unknown in one case (65-69 years of age) and one case in the diagnosis file was not in the patient file so could not be allocated an age or sex.

58 per cent of cases of oral cavity cancer were male.

14 per cent of patients were aged under 50 years.

The median ages were; for males 62 years and females 68 years.

14 per cent of male cases were under the age of 50, 17 per cent were aged over.

13 per cent of female cases were under the age of 50. 46 per cent were aged over 75.

The apparent trend seen in last year’s report of a second peak of registrations in elderly females is again seen in this year’s data, and in the combined data from the audit’s inception. However, further analysis of this trend is discussed below.

National Head and Neck Cancer Audit registrations are broadly in line with ONS which reports rates of oral cancer in men approximately double that in women at the age of 50, but approximately equal over the age of 80.

The fact that more cancer cases have been recorded in older females than older males is accounted for by the greater life expectancy of females, and consequently there is a larger population of women over the age of 80 than of men.
• The ratio of male to female oral cavity cancers exceeds the ratio of males to females in England and Wales by a factor of approximately 2 between the ages of 40 and 80. This suggests that the risk of oral cavity cancer in males is approximately double than in females between the ages of 40 and 80; beyond this age risk is approximately equal. Using national age-sex distribution in each age band, a better comparison of true incidence can be made.
Findings

- Cumulative data of over 2,500 cases from the inception of the audit shows similar distributions by age band supporting the findings above and confirming contribution from a homogenous population.

- A sub analysis showed no significant difference in age distribution between England and Wales.

- The incidence of oral cavity cancers occurs over a broader age range (compared to laryngeal cancer) between the ages of 45 and 85, and any future proposals in relation to screening (as proposed in the Cancer Reform Strategy) if applied to oral cavity cancer would need to screen a wide age group.

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). Three consecutive year’s data have failed to demonstrate this phenomenon in England and Wales. Registrations again do not appear to confirm the trend of a rising occurrence in young people. However, not all cases have been registered in this time frame particularly in the South of England where figures support a higher incidence in London and the South East for 13 to 24 year olds across non thyroid head and neck anatomic sites.
8.4.2 Distribution of stage

8.4.2.1 Larynx

8.4.2.1.1 Stage at diagnosis

- Recording of staging continues to improve.
- Over 76.5 per cent had T and N category recorded.
- Overall 14.5 per cent of larynx cancers were node positive at presentation.
- Analysis by sub-site of primary showed, for glottic cancers, 35 of 547 cases to be node positive at diagnosis, compared to 99 of 258 cases of supraglottic cancer, with 18 larynx NOS (not specified). This demonstrates the greater propensity of supraglottic cancer compared to glottic cancer to involve regional nodes.
- 1.6 cent were M1, confirming the low propensity of laryngeal carcinomas of presenting with distant metastatic disease.

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<th>T3</th>
<th>T4</th>
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<td>11.3</td>
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<td>0.1</td>
<td>1.0</td>
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<td>3.8</td>
<td>6.3</td>
<td>4.9</td>
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<td>15.5</td>
<td>11.7</td>
<td>5.0</td>
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</table>

Percentage of 1,049 recorded cases
65.5 per cent of laryngeal cancers have stage at diagnosis recorded to allow categorisation into low stage and high stage disease (thus excluding Tx and Nx).

34.5 per cent of laryngeal cancers have no staging recorded, or insufficient information to categorise stage. The figures show an improvement on the previous year (2005-2006 44.5 per cent) which is encouraging, but considerable further work is required to meet universal stage recording.

In laryngeal cancer, as previously found, early stage disease predominates.7,8

**Good Practice Standard**

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 per cent of cases staged in any high quality database collection, to allow valid comparisons to be made.

**8.4.2.1.2 Comparison of stage at diagnosis and post-surgery staging**

Of the 255 patients recorded as undergoing surgery (202 with curative intent), information on stage at diagnosis, with post surgical staging (ie based on resective pathology), was available for T category in 185 patients and N category in 179 patients.

Of the 185 patients where staging was recorded 72 underwent laser surgery.

- In T category, 8 patients were upstaged following surgery, and 5 downstaged.

**Figure 8.4.2.1.2.a: Comparison of stage at diagnosis and post-surgery staging.**

### Post-surgery

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<tr>
<td>TX</td>
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<tr>
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**Figure 8.4.2.1.2.b: Comparison of stage at diagnosis and post-surgery staging.**

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<td>N3</td>
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</tr>
<tr>
<td>Total</td>
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</tr>
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</table>

- 4 patients were upstaged and 3 patients were downstaged, which shows a level of correlation expected rather than the previous absence of any change in N category. The sample size, however, is too small and incomplete at this stage to draw any definitive conclusions.

- As expected only a small number of patients with very advanced neck disease staging recorded (N3) underwent surgical treatment.

**8.4.2.1.3 Summary of recorded stage certainty**

Percentage of cases with recorded T N M category (452 T category recorded; 434 N category recorded; 410 M category recorded).

**Figure 8.4.2.1.3.a: Summary of recorded stage certainty.**

<table>
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<tr>
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<th>Stage Certainty</th>
<th>Not Recorded</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Cases with recorded N</td>
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<td>22.1</td>
</tr>
<tr>
<td>Cases with recorded M</td>
<td>16.8</td>
<td>18.2</td>
</tr>
</tbody>
</table>

- 43.1 per cent had T stage certainty factor recorded, 41.4 per cent had N stage certainty factor recorded and 39.1 per cent had M stage certainty factor recorded.

- This is a significant decline this year in the recording of this item and the relevance of this item will be raised in future workshops.

- 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.
Findings

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. 29

- Less than half of laryngeal cases had certainty factor completed, which is a reverse of previous progress. It would be expected that the numbers with C4 should be greater based on the number of resective procedures performed.

Good Practice Standard
For those cases undergoing surgical management it is important that resective pathology is accurately recorded to allow true stage comparison. Surgical teams should develop responsibilities in this key area.

8.4.2.2 Oral cavity

8.4.2.2.1 Stage at diagnosis

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<th>T Category</th>
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<tbody>
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<td>0.1</td>
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<tr>
<td>Total</td>
<td>29.2</td>
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</tr>
</tbody>
</table>

- 78 per cent had T and N category recorded.
- 22 per cent were N positive at diagnosis.
- Analysis by sub-site of primary showed, for glottic cancers, 35 of 547 cases to be node positive at diagnosis, compared to 99 of 258 cases of supraglottic cancer, with 18 larynx NOS (not specified). This demonstrates the greater propensity of supraglottic cancer compared to glottic cancer to involve regional nodes.
- Of the 215 cases of oral cavity cancer which were node positive at diagnosis, there was a more even distribution of associated primary site. However, the most common primary sites associated with regional metastasis were floor of mouth and retromolar trigone.
- 1.0 per cent were M1, confirming the low propensity of oral cavity carcinomas to present with distant metastatic disease.
Findings

64.8 per cent of oral cavity cancers have stage at diagnosis recorded to allow categorisation into low and high stage disease (thus excluding Tx and Nx).

35.2 per cent of oral cancers have no staging recorded, or insufficient information to categorise stage. The figures show an improvement on the previous year (2005-2006, 41.5 per cent) which is encouraging.

The previously noted dominance of late stage cancer (2004-2005 report) is not evident again in this year’s data. As the level of staging rises the finding of a predominance of early stage cancer is supported. However, no firm conclusion can be drawn due to the level of no stage recorded or insufficient TNM to categorise.

8.4.2.2 Comparison of stage at diagnosis and post-surgery staging

Of the 531 patients recorded as undergoing surgery, information on stage at diagnosis, with post surgical staging (ie based on resective pathology), was available for T category in 362 patients and N category in 358 patients.

- 68 per cent of patients undergoing surgery had post resective surgery staging details recorded.

Good Practice Standard

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 per cent of cases staged in any high quality database collection, to allow valid comparisons to be made.

Figure 8.4.2.1.b: Oral Cavity, Stage at diagnosis.
Findings

Figure 8.4.2.2.2.a: Comparison of stage at diagnosis and post-surgery staging.

<table>
<thead>
<tr>
<th>T</th>
<th>Diagnosis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>138</td>
<td>157</td>
</tr>
<tr>
<td>T2</td>
<td>90</td>
<td>101</td>
</tr>
<tr>
<td>T3</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>T4</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>TX</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>147</td>
<td>362</td>
</tr>
</tbody>
</table>

Figure 8.4.2.2.2.b: Comparison of stage at diagnosis and post-surgery staging.

<table>
<thead>
<tr>
<th>N</th>
<th>Diagnosis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N0</td>
<td>224</td>
<td>232</td>
</tr>
<tr>
<td>N1</td>
<td>33</td>
<td>45</td>
</tr>
<tr>
<td>N2</td>
<td>41</td>
<td>61</td>
</tr>
<tr>
<td>N3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>NX</td>
<td>13</td>
<td>18</td>
</tr>
<tr>
<td>Not Recorded</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>245</td>
<td>358</td>
</tr>
</tbody>
</table>

- In T category, 14 patients were upstaged following surgery and 23 were downstaged (10 per cent change in stage).

8.4.2.2.3 Summary of recorded stage certainty

Percentages of cases with recorded T N M (519 T category recorded; 508 N category recorded and 487 M category recorded).

Figure 8.4.2.2.3.a: Summary of recorded stage certainty.

<table>
<thead>
<tr>
<th>Stage Category</th>
<th>C1</th>
<th>C2</th>
<th>C3</th>
<th>C4</th>
<th>Not Recorded</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cases with recorded T</td>
<td>14.7</td>
<td>16.1</td>
<td>16.4</td>
<td>5.4</td>
<td>47.4</td>
<td>100</td>
</tr>
<tr>
<td>Cases with recorded N</td>
<td>16.2</td>
<td>27.2</td>
<td>5.0</td>
<td>3.1</td>
<td>48.5</td>
<td>100</td>
</tr>
<tr>
<td>Cases with recorded M</td>
<td>24.7</td>
<td>19.5</td>
<td>4.8</td>
<td>0.4</td>
<td>50.6</td>
<td>100</td>
</tr>
</tbody>
</table>

- 52.6 per cent had T stage certainty factor recorded, 51.5 per cent had N stage certainty factor recorded and 49.4 per cent had M stage certainty factor recorded.
- This is a significant decline this year in the recording of this item and the relevance of this item will be raised in future workshops.
- 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.

- 27 patients were upstaged and 8 patients were downstaged (10 per cent change in stage). This is consistent with last year’s data. The sample size, however, is too small and incomplete at this stage to draw any definitive conclusions.
- The number of patients upstaged following surgery seems low compared to published estimates of occult metastasis in squamous cell carcinoma of the oral cavity. Given the predominance of cancer of the tongue in the cases submitted it might be expected that higher percentage of upstaging would be seen.

- Just over a half of oral cases had certainty factor completed, which represents a reverse of previous progress. It would be expected that the numbers with C4 should be greater based on the number of resective procedures performed.

Good Practice Standard

For those cases undergoing surgical management, it is important that resective pathological staging is accurately recorded to allow true stage comparison. Surgical teams should take responsibility in this area and, in particular, should ensure that the certainty factor is also accurately recorded.
Findings

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 |

8.4.2.3 Comparison of low to high stage disease by tumour site

The rise in the level of staging submission allows a comparison of early versus late disease by site for this year's data.

<table>
<thead>
<tr>
<th>Site</th>
<th>Low Stage</th>
<th>High Stage</th>
<th>Stage Unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Larynx</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glottis</td>
<td>291</td>
<td>116</td>
<td>140</td>
<td>547</td>
</tr>
<tr>
<td>Supraglottis</td>
<td>59</td>
<td>132</td>
<td>67</td>
<td>258</td>
</tr>
<tr>
<td>Larynx, unspecified</td>
<td>46</td>
<td>54</td>
<td>103</td>
<td>203</td>
</tr>
<tr>
<td>Anterior surface of epiglottis</td>
<td>2</td>
<td>5</td>
<td>15</td>
<td>22</td>
</tr>
<tr>
<td>Subglottis</td>
<td>10</td>
<td>4</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>408</td>
<td>311</td>
<td>330</td>
<td>1,049</td>
</tr>
<tr>
<td><strong>Oral Cavity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Border of tongue</td>
<td>134</td>
<td>50</td>
<td>52</td>
<td>236</td>
</tr>
<tr>
<td>Anterior floor of mouth</td>
<td>45</td>
<td>21</td>
<td>31</td>
<td>97</td>
</tr>
<tr>
<td>Ventral surface of tongue</td>
<td>38</td>
<td>20</td>
<td>30</td>
<td>88</td>
</tr>
<tr>
<td>Cheek mucosa</td>
<td>34</td>
<td>26</td>
<td>24</td>
<td>84</td>
</tr>
<tr>
<td>Hard palate</td>
<td>21</td>
<td>23</td>
<td>25</td>
<td>69</td>
</tr>
<tr>
<td>Dorsal surface of tongue</td>
<td>23</td>
<td>18</td>
<td>26</td>
<td>67</td>
</tr>
<tr>
<td>Lower gum</td>
<td>11</td>
<td>41</td>
<td>7</td>
<td>59</td>
</tr>
<tr>
<td>Retromolar area</td>
<td>14</td>
<td>26</td>
<td>14</td>
<td>54</td>
</tr>
<tr>
<td>Overlapping lesion of floor of mouth</td>
<td>17</td>
<td>15</td>
<td>15</td>
<td>47</td>
</tr>
<tr>
<td>Lateral floor of mouth</td>
<td>18</td>
<td>9</td>
<td>10</td>
<td>37</td>
</tr>
<tr>
<td>Upper lip, inner aspect</td>
<td>12</td>
<td>6</td>
<td>17</td>
<td>35</td>
</tr>
<tr>
<td>Upper gum</td>
<td>13</td>
<td>17</td>
<td>5</td>
<td>35</td>
</tr>
<tr>
<td>Vestibule of mouth</td>
<td>7</td>
<td>18</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Overlapping lesion of tongue</td>
<td>5</td>
<td>12</td>
<td>16</td>
<td>33</td>
</tr>
<tr>
<td>Lower lip, inner aspect</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Mouth unspecified</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Oral Cavity Total</strong></td>
<td>395</td>
<td>303</td>
<td>288</td>
<td>986</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>803</td>
<td>614</td>
<td>618</td>
<td>2,035</td>
</tr>
</tbody>
</table>
• In larynx cancer for glottic cancer low stage disease predominates (2.5 to 1), whilst in supraglottic cancer high stage disease is the commoner (2.2 to 1).

• In oral cavity cancer for the tongue and anterior/lateral floor of mouth and inner aspect of lip low stage disease predominates, whilst in the remaining sites high stage disease is more frequent.

• However, no firm conclusion can be drawn due to the level of no stage recorded or insufficient TNM to categorise.

8.4.2.4 Submission by Cancer Network of patients with new head and neck primaries of the larynx and oral cavity by ratio of low to high stage disease January 2004-October 2007

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>Low Stage</th>
<th>High Stage</th>
<th>Unknown Stage</th>
<th>Total</th>
<th>Low:High ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Counties</td>
<td>27</td>
<td>12</td>
<td>23</td>
<td>62</td>
<td>2.3</td>
</tr>
<tr>
<td>Arden</td>
<td>11</td>
<td>15</td>
<td>86</td>
<td>112</td>
<td>0.7</td>
</tr>
<tr>
<td>Avon Somerset and Wiltshire</td>
<td>41</td>
<td>29</td>
<td>87</td>
<td>157</td>
<td>1.4</td>
</tr>
<tr>
<td>Central South Coast</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>9</td>
<td>1.0</td>
</tr>
<tr>
<td>Derby Burton</td>
<td>80</td>
<td>84</td>
<td>10</td>
<td>174</td>
<td>1.0</td>
</tr>
<tr>
<td>Dorset</td>
<td>71</td>
<td>35</td>
<td>11</td>
<td>117</td>
<td>2.0</td>
</tr>
<tr>
<td>Greater Manchester and Cheshire</td>
<td>28</td>
<td>20</td>
<td>92</td>
<td>140</td>
<td>1.4</td>
</tr>
<tr>
<td>Greater Midlands</td>
<td>8</td>
<td>7</td>
<td>50</td>
<td>65</td>
<td>1.1</td>
</tr>
<tr>
<td>Humber and Yorkshire Coast</td>
<td>21</td>
<td>24</td>
<td>28</td>
<td>73</td>
<td>0.9</td>
</tr>
<tr>
<td>Kent and Medway</td>
<td>7</td>
<td>5</td>
<td>35</td>
<td>47</td>
<td>1.4</td>
</tr>
<tr>
<td>Lancashire and South Cumbria</td>
<td>10</td>
<td>5</td>
<td>35</td>
<td>50</td>
<td>2.0</td>
</tr>
<tr>
<td>Leicestershire, Northamptonshire and Rutland</td>
<td>85</td>
<td>87</td>
<td>65</td>
<td>237</td>
<td>1.0</td>
</tr>
<tr>
<td>Merseyside and Cheshire</td>
<td>184</td>
<td>112</td>
<td>106</td>
<td>402</td>
<td>1.6</td>
</tr>
<tr>
<td>Mid Anglia</td>
<td>30</td>
<td>40</td>
<td>53</td>
<td>123</td>
<td>0.8</td>
</tr>
<tr>
<td>Mid Trent</td>
<td>108</td>
<td>85</td>
<td>93</td>
<td>286</td>
<td>1.3</td>
</tr>
<tr>
<td>Mount Vernon</td>
<td>16</td>
<td>19</td>
<td>17</td>
<td>52</td>
<td>0.8</td>
</tr>
<tr>
<td>Norfolk and Waveney</td>
<td>44</td>
<td>33</td>
<td>36</td>
<td>113</td>
<td>1.3</td>
</tr>
<tr>
<td>North East London</td>
<td>12</td>
<td>6</td>
<td>4</td>
<td>22</td>
<td>2.0</td>
</tr>
<tr>
<td>North London</td>
<td>2</td>
<td>5</td>
<td>0</td>
<td>7</td>
<td>0.4</td>
</tr>
<tr>
<td>North Trent</td>
<td>73</td>
<td>53</td>
<td>41</td>
<td>167</td>
<td>1.4</td>
</tr>
<tr>
<td>Northern</td>
<td>154</td>
<td>151</td>
<td>57</td>
<td>362</td>
<td>1.0</td>
</tr>
<tr>
<td>Pan Birmingham</td>
<td>177</td>
<td>148</td>
<td>42</td>
<td>367</td>
<td>1.2</td>
</tr>
<tr>
<td>Peninsula</td>
<td>122</td>
<td>93</td>
<td>85</td>
<td>300</td>
<td>1.3</td>
</tr>
<tr>
<td>South East London</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0.0</td>
</tr>
<tr>
<td>South Essex</td>
<td>32</td>
<td>18</td>
<td>0</td>
<td>50</td>
<td>1.8</td>
</tr>
<tr>
<td>South West London</td>
<td>85</td>
<td>66</td>
<td>16</td>
<td>167</td>
<td>1.3</td>
</tr>
<tr>
<td>Surrey, West Sussex and Hants</td>
<td>28</td>
<td>23</td>
<td>12</td>
<td>63</td>
<td>1.2</td>
</tr>
<tr>
<td>Sussex</td>
<td>36</td>
<td>29</td>
<td>61</td>
<td>126</td>
<td>1.2</td>
</tr>
<tr>
<td>Teesside, South Durham and North Yorkshire</td>
<td>51</td>
<td>42</td>
<td>181</td>
<td>274</td>
<td>1.2</td>
</tr>
<tr>
<td>Thames Valley</td>
<td>23</td>
<td>29</td>
<td>84</td>
<td>136</td>
<td>0.8</td>
</tr>
<tr>
<td>West Anglia</td>
<td>67</td>
<td>34</td>
<td>28</td>
<td>129</td>
<td>2.0</td>
</tr>
<tr>
<td>West London</td>
<td>18</td>
<td>7</td>
<td>2</td>
<td>27</td>
<td>2.6</td>
</tr>
<tr>
<td>Yorkshire</td>
<td>210</td>
<td>186</td>
<td>118</td>
<td>514</td>
<td>1.1</td>
</tr>
</tbody>
</table>

| England Total                               | 1,864      | 1,506      | 1,561         | 4,931 | 1.2            |
In preparation for future risk adjustment, a comparison of pooled submission since the inception of the audit by network of the ratio of low to high stage disease was made to understand variation in presentation of the stage of disease.

The higher the ratio, the greater the predominance of low stage disease.

Caution should be made in interpreting data from networks whose submission rates or level of recording stage are poor.

### 8.4.2.5 Submission by Cancer Network of patients who underwent surgery of the larynx and oral cavity where recording of pre treatment and post resective pathological staging is identified in the index period

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>T and N recorded pre-treatment</th>
<th>Number with surgery</th>
<th>T and N recorded post-surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Counties</td>
<td>40</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>Arden</td>
<td>15</td>
<td>27</td>
<td>7</td>
</tr>
<tr>
<td>Avon Somerset and Wiltshire</td>
<td>77</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Central South Coast</td>
<td>7</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Derby Burton</td>
<td>66</td>
<td>53</td>
<td>42</td>
</tr>
<tr>
<td>Dorset</td>
<td>46</td>
<td>24</td>
<td>23</td>
</tr>
<tr>
<td>Greater Manchester and Cheshire</td>
<td>8</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Greater Midlands</td>
<td>12</td>
<td>27</td>
<td>3</td>
</tr>
<tr>
<td>Humber and Yorkshire Coast</td>
<td>44</td>
<td>17</td>
<td>16</td>
</tr>
<tr>
<td>Kent and Medway</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Lancashire and South Cumbria</td>
<td>20</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Leicestershire, Northamptonshire and Rutland</td>
<td>73</td>
<td>41</td>
<td>38</td>
</tr>
<tr>
<td>Merseyside and Cheshire</td>
<td>39</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mid Anglia</td>
<td>13</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>Mid Trent</td>
<td>97</td>
<td>52</td>
<td>40</td>
</tr>
<tr>
<td>Mount Vernon</td>
<td>19</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Norfolk and Waveney</td>
<td>44</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>North East London</td>
<td>16</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>North Trent</td>
<td>52</td>
<td>26</td>
<td>21</td>
</tr>
</tbody>
</table>
Findings

Of the 1,550 diagnoses where T and N staging category were recorded, 787 underwent surgery. Of the 787 surgical cases, all of which would be expected to have resective pathological staging (pTNM), 544 had post surgery T and N category recorded. This represents 69 per cent of the surgical treatment group.

pTNM remains the gold standard in the staging of cancer and networks should encourage collection of this important item in the analysis of survival and treatment effectiveness.

12 networks show high levels of post surgery T and N category and are to be congratulated.

8.4.3 Distribution of performance status at point of treatment decision

Larynx

Cancer Networks are shown as defined at the start of the index period November 2006. Note pre-surgery data is by provider hospital whereas post surgery data is by treating hospital.
Oral cavity

Figure 8.4.3.b: Oral Cavity; Distribution of performance status at point of treatment decision.

<table>
<thead>
<tr>
<th>Performance status</th>
<th>Percentage of 477 recorded values</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. Able to carry out all normal activity without restriction</td>
<td>55.7</td>
</tr>
<tr>
<td>1. Restricted in physically strenuous activity</td>
<td>16.4</td>
</tr>
<tr>
<td>2. Able to walk and capable of all self care but unable to carry out any work</td>
<td>9.0</td>
</tr>
<tr>
<td>3. Capable of only limited self care</td>
<td>5.0</td>
</tr>
<tr>
<td>4. Completely disabled</td>
<td>0.2</td>
</tr>
<tr>
<td>5. Not recorded</td>
<td>13.7</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
</tr>
</tbody>
</table>

- 1,732 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).

- 951 patients had performance status recorded, which is 46.7 per cent of the total registrations. This equates to 55 per cent of patients with a recorded careplan.

- The completion of performance status remains poor.

- To facilitate risk adjustment further training on performance status and completeness is required. The figures for the first two annual reports 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 co-morbidity at index point of diagnosis (ACE-27)

A description of the Adult Comorbidity index (ACE-27) can be found in Appendix 7.

Larynx

- 891 patients had at least one careplan.

- 302 patients had co-morbidity index recorded. This is 34 per cent of patients with a recorded careplan, which is 28 per cent of total registrations.

8.4.4.1 Summary of recorded co-morbidity

Figure 8.4.4.1.a: Larynx; Summary of recorded co-morbidity

<table>
<thead>
<tr>
<th>Grade</th>
<th>Percentage of 302 recorded values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 0 - No co-morbidity</td>
<td>43.0</td>
</tr>
<tr>
<td>Grade 1 - Mild decompensation</td>
<td>33.1</td>
</tr>
<tr>
<td>Grade 2 - Moderate decompensation</td>
<td>14.2</td>
</tr>
<tr>
<td>Grade 3 - Severe decompensation</td>
<td>9.6</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Oral Cavity

- 841 patients had at least one careplan.
- 352 patients had co-morbidity index recorded. This is 42 per cent of patients with a recorded careplan, which is 36 per cent of total registrations.

Co-morbidity 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. All MDT’s are encouraged to collect co-morbidity data.

- The figures in this year’s report do not show the previously noted greater frequency of moderate and severe decompensation. The figures are closer to those of a previous UK population of larynx only cancer patients studied 32,33.
- The figures for co-morbidity suggest that 48 per cent of the total population (larynx and oral cavity) patients had no co-morbidity. This appears to tally with the normal performance status in the previous output (8.4.3) and the reported figure last year.

8.4.5  Deprivation analysis: Distribution of diagnosis, treatment and outcome by socio-economic Lower Super Output Areas, derived from the postcode in England and Wales

The Index of Multiple Deprivation 2004 (IMD 2004) was used as a measure of socio-economic deprivation and is applicable in England 34,35. The Welsh Index of Multiple Deprivation (WIMD 2005) was used as a measure of socio-economic deprivation and is applicable to Wales. Both indices are not directly comparable due to the differing proportion of the domains that make up the index for each country.

The lower the index score the greater the level of deprivation for each Lower Super Output Area (LSOA). For each country, these LSOAs were split into quintiles based on the same number of LSOAs (or as close to as possible) being in each quintile, thus the first quintile represents those who are most deprived. Each registration was assigned a quintile of deprivation.

To investigate any bias that may be caused by the partial coverage of the National Head and Neck Cancer Audit, the registrations have been totalled by the average deprivation of their PCT of residence. A deprivation score is attributed to (English) PCTs according to the population weighted mean score of the Lower Super Output Areas that make up that PCT. PCTs were then ranked and categorised into quintiles. The total registrations by PCT deprivation are below, and show no particular bias.
8.4.5.1 Summary of registrations by deprivation in England

- As previously the distribution of cases is more even across the deprivation quintiles for both larynx and oral cavity, though a greater number of larynx registrations reside in areas of relative deprivation (quintiles 1 and 2).
8.4.5.2 Deprivation and stage in England

Figure 8.4.5.2.a: Deprivation and stage in England.

The lower chart (Figure 8.4.5.2.b) demonstrates for each quintile the percentage of registrants who have staging information recorded, this demonstrates similar proportions across the quintiles showing the upper graph (Figure 8.4.5.2.a) is not biased by incomplete staging.
Findings

Of the overall 2,035 patients, 1,773 had a postcode that could be classified into a LSOA and had staging recorded to allow classification early or late stage disease (885 larynx cancer and 888 oral cavity cancer). The rise in the percentage of staging reinforces the indication (seen in last years report) that at diagnosis late stage cancer is more likely in the most deprived, while amongst the least deprived low stage cancer is more common. Across all quintiles however low stage disease is numerically greater.

8.4.5.3 Deprivation and interval from onset of first symptom to referral in England

Figure 8.4.5.3.a: Larynx and Oral Cavity - Interval from first symptom to referral by socio-economic deprivation in England (765 cases had date of first symptom recorded).

- It has been previously proposed that deprivation has a bearing on delayed presentation and delayed onward referral.
- The interval to first symptom has reduced significantly for oral cavity cancer in the last year, where in all deprivation quintiles it now appears as a shorter interval than in larynx cancer.
- The reasons for the above are not clear but may reflect a larger sample size or an improvement in patient access or pathway intervals.
- No clear relationship is shown between the interval from onset of first symptom to referral and deprivation for larynx or oral cavity cancer.
Findings

8.4.5.4 Deprivation and interval from referral to treatment in England

- The interval from referral to first recorded treatment by deprivation quintile shows near identical median values between the most deprived and least, which is comparable to last year’s sample.
Findings

The interval from referral to first recorded treatment by deprivation quintile shows a 6 day difference in median value (least deprived 54 days compared to 60 days for the most deprived). This is in contrast to a 20 day difference between the most deprived and least deprived evident in the first annual report, and equivalence last year. This item will continue to be evaluated, but is encouraging that delayed access seen in the first annual report appears to be reducing.

8.4.5.5 Proportion of registrations in each Cancer Network in England and Wales by quintile of deprivation January 2004-October 2007

- A comparison between networks in England since the inception of the audit who have submitted greater than 20 larynx or oral cavity cases are shown in the rainbow charts. The total number of cases submitted is shown at the top of the column.
- The small numbers in some networks mean that selection bias may influence the comparison.
- Differences in deprivation will be utilised in calculating risk adjustment in future reports.
- Differences in deprivation may influence the level of support particularly for social care required by each network for its head and neck services.
In larynx cancer, the most deprived have a greater prevalence in the North of England, being 20 per cent above the England average in some networks.

In larynx cancer, the least deprived have a greater prevalence in the South of England, being 15 to 30 per cent below the England average in some networks.
- In oral cavity cancer, the most deprived have a greater prevalence again in the North of England, being 10 to 15 per cent above the England average in some networks.

- In oral cavity cancer, the least deprived have a greater prevalence in the South of England, being 15 to 30 per cent below the England average in some networks.
In larynx and oral cavity in Wales, the most deprived have a greater prevalence in the South East of Wales, being 5 per cent above the Wales average however this has the greatest area of population density.
8.5  The patient journey - diagnostic and staging process, waiting intervals

8.5.1  Source of referral to specialist team in England

8.5.1.1 Larynx

<table>
<thead>
<tr>
<th>Primary referral source</th>
<th>2ww from GP or dentist</th>
<th>Other</th>
<th>Not recorded</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>451</td>
<td>250</td>
<td>7</td>
<td>708</td>
</tr>
<tr>
<td>Emergency / A&amp;E</td>
<td>1</td>
<td>36</td>
<td>1</td>
<td>38</td>
</tr>
<tr>
<td>Consultant referral</td>
<td>2</td>
<td>212</td>
<td>6</td>
<td>220</td>
</tr>
<tr>
<td>Self / Other</td>
<td>37</td>
<td>37</td>
<td>2</td>
<td>76</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>33</td>
<td>1</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>456</td>
<td>568</td>
<td>17</td>
<td>1,041</td>
</tr>
</tbody>
</table>

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- There is a ratio of 1.75:1 in referral via the two week wait urgent referral pathway compared to other referral priorities, in referrals from general practitioners in those with diagnosed cancer. Other network based reviews have also shown that the non two week referral pathway remains the commonest route in those diagnosed with head and neck cancer. This compares in 2006 to 1.49:1, and 1.7:1 in 2005 suggesting that two week wait referrals from GPs as a source for diagnosed cancers have returned to levels seen in 2005.

8.5.1.2 Oral cavity

<table>
<thead>
<tr>
<th>Primary referral source</th>
<th>Two week wait from GP or dentist</th>
<th>Other</th>
<th>Not recorded</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>332</td>
<td>150</td>
<td>4</td>
<td>486</td>
</tr>
<tr>
<td>GDP / CDS</td>
<td>39</td>
<td>127</td>
<td>1</td>
<td>167</td>
</tr>
<tr>
<td>Emergency / A&amp;E</td>
<td>1</td>
<td>16</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>Consultant referral</td>
<td>4</td>
<td>188</td>
<td>1</td>
<td>193</td>
</tr>
<tr>
<td>Self / Other</td>
<td></td>
<td>56</td>
<td></td>
<td>56</td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td>36</td>
<td>12</td>
<td>48</td>
</tr>
<tr>
<td>Total</td>
<td>376</td>
<td>573</td>
<td>18</td>
<td>567</td>
</tr>
</tbody>
</table>

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.
• There is a ratio of 2.16:1 in referral via the two week wait urgent referral pathway compared to other referral priorities, in referrals from general medical practitioners in those with diagnosed cancer, and a ratio of 0.30:1 for those referred under the two week wait from general dental practitioners (GDP) / Community Dental Services (CDS). From consideration of the submitted data and informal feedback from the Expert Panels, general dental practitioners do not appear to be embracing the two week wait referrals pathway in some networks and in others are not actively involved in the process. Cancer Networks should consider a strategy to enhance the role of the GDP in the cancer referral process. The audit, however, has not sampled the total number of referrals from which these derived.

• In 2006 the ratio was 2.02:1, suggesting a similar proportion of patients with cancer are being referred via the two week wait rule from general practitioners. Further education is required to enable practitioners to recognise alarm symptoms and utilise the two week wait referral pathway.

8.5.2 Summary as percentage of cases with both ‘primary referral priority’ and ‘primary referral source’ completed in England

8.5.2.1 Larynx

<table>
<thead>
<tr>
<th>Primary referral source</th>
<th>Two week wait from GP or dentist</th>
<th>Other priority</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>45.6</td>
<td>25.3</td>
<td>70.9</td>
</tr>
<tr>
<td>GDP / CDS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency / A&amp;E</td>
<td>0.1</td>
<td>3.6</td>
<td>3.7</td>
</tr>
<tr>
<td>Consultant referral</td>
<td>0.2</td>
<td>21.4</td>
<td>21.6</td>
</tr>
<tr>
<td>Self / Other</td>
<td></td>
<td>3.7</td>
<td>3.7</td>
</tr>
<tr>
<td>Total</td>
<td>45.9</td>
<td>54.1</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

• 70.9 per cent of those diagnosed with laryngeal cancer are referred by their general practitioner, whilst of the remaining 29.1 per cent, 21.6 per cent are referred from another consultant.
8.5.2.2 Oral cavity

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- 52.8 per cent of those diagnosed with oral cavity cancer are referred by their general practitioner. Of the remaining 47.2 per cent, 21 per cent are referred from another consultant and 18 per cent from a general dental practitioner or the Community Dental Service. However, 14 per cent of these were not referred using an urgent referral pathway. The important role of general dental services in screening for oral cavity cancer is recognised, but further work is required to ensure referral urgency is appropriately applied.
8.5.3 Interval from first symptom to referral to specialist team

Patient recall of the onset of their first symptom to their point of referral is a crude indicator of patient awareness. The figures presented continue to suggest earlier presentation of oral cavity cancer (median interval 54 days) compared to laryngeal cancer (median interval 76 days). This shows a similar difference to the first and second annual reports confirming a trend. This may be because within the oral cavity, cancers are more visible.
Findings

• The second chart shows data from the inception of the audit from 2,146 patients. The cumulative findings confirm consistency of median times from first symptom to referral for both larynx and oral cavity cancer, in cases from 2004 to 2007.

• The significance of delay in outcome and stage at presentation remains controversial.

• 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
8.5.4 Interval from referral to first appointment in England

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- The figure shows that for non two week wait referrals, 30 per cent have an interval from referral to first appointment of 0 days. This reflects self referrals, referrals to an Accident 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 England in December 2000. This is designed to speed up the patient’s entry into the cancer care pathway and improve outcomes, though this has not been demonstrated in other cancers. 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. Again, however 20 per cent of other referrals in the sample are waiting over one month for their first appointment, and would imply 10 per cent of 2 week wait patients are waiting over 14 days. The latter are not adjusted times and therefore do not take into account patients choosing to wait over 14 days and those not attending first appointments. National cancer waiting times, which take account of adjustments, show 100 per cent of those received within 24 hours and 93 per cent of those not received within 24 hours being seen within 14 days for two week wait patients.

- With the implementation of national referral guidelines in England, (Guidance on Cancer Services - Improving Outcomes in Head and Neck Cancers and Referral Guidelines for Suspected Cancers), it would be expected that an ever increasing proportion of patients will be referred via the two-week wait pathway but this is not borne out in this third period of data collection.
The introduction of Choose and Book has placed upon the referrer the responsibility of requesting urgent priority for symptoms not falling into the two week wait criteria rather than a reliance upon triage. Further reductions in cancer waiting times have been announced in the Cancer Reform Strategy to be implemented by December 2008.

- The importance of alarm symptoms and their usage by general practitioners has again been made with the recognition that the diagnosis of cancer by an individual GP is still rare.

- Understanding is growing of factors responsible for recognition of signs and symptoms in patients that encourage a visit to a doctor and dentist. Furthermore, the variation of the interval from first recognition of suspicious symptoms to diagnosis, as shown by this audit, begs questions of the psychological response to possible malignancy, not only by patients but also care-givers.

8.5.5 Interval from referral to diagnosis in England and Wales

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 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.

Anxiety promoted by uncertainty is acknowledged as the major psychological distress experience by patients following referral to specialist services for diagnostic investigation. This anxiety often reaches levels where clinical intervention is indicated. Reducing the interval between referral and diagnosis will attenuate ‘case’ level anxiety.

Figure 8.5.5.a: Interval from referral to diagnosis in England and Wales.
• 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. There have been small decreases for both larynx and oral cavity cancers in the time taken from referral to diagnosis in this period of data collection.

• 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 95 per cent of patients reach a diagnosis by 100 days and then plateaux.

8.5.5.1 Time from biopsy to reporting

This item represents the time from the biopsy being taken to its reporting.

- The median time from biopsy to its reporting is 3 days for larynx.
- There has been a general shift to the left in the graphical appearance ie same day reporting is significantly higher. The Head and Neck Clinical Reference Group noted the latter and considered this may reflect same day cytology reporting, frozen section (in a small number of patients) or data quality as fixing and staining of specimens takes more than 24 hours.
- The chart below reports, by trust, a breakdown for larynx of the interval from biopsy to reporting of 10 days or less and greater than 10 days. Only those organisations contributing data on over 5 cases are presented. These organisations are to be congratulated in this area and it should be acknowledged that non-submitters’ interval to reporting could be considerably poorer than the organisations presented.
• The chart is colour coded to show quartiles as follows;

**Key:**  
- **Green** = trusts where less than 25 per cent of cases have taken more than 10 days  
- **Amber** = trusts with less than 50 per cent but greater than or equal to 25 per cent which have taken more than 10 days  
- **Red** = trusts with greater than or equal to 50 per cent of cases which have taken more than 10 days

**Figure 8.5.5.1.b:** Time from biopsy to reporting by trust, for those trusts reporting greater than 5 larynx cases

<table>
<thead>
<tr>
<th>Hospital Trust</th>
<th>Number &lt;=10 days</th>
<th>% &lt;=10 days</th>
<th>Number &gt;10 days</th>
<th>% &gt;10 days</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barking Havering and Redbridge Hospitals NHS Trust</td>
<td>7</td>
<td>77.8</td>
<td>2</td>
<td>22.2</td>
<td>9</td>
</tr>
<tr>
<td>Bradford Hospitals NHS Trust</td>
<td>13</td>
<td>72.2</td>
<td>5</td>
<td>27.8</td>
<td>18</td>
</tr>
<tr>
<td>Brighton and Sussex University Hospitals NHS Trust</td>
<td>10</td>
<td>100.0</td>
<td>0</td>
<td>0.0</td>
<td>10</td>
</tr>
<tr>
<td>City Hospitals Sunderland NHS Trust</td>
<td>15</td>
<td>93.8</td>
<td>1</td>
<td>6.3</td>
<td>16</td>
</tr>
<tr>
<td>East Sussex Hospitals NHS Trust</td>
<td>10</td>
<td>83.3</td>
<td>2</td>
<td>16.7</td>
<td>12</td>
</tr>
<tr>
<td>Gloucestershire Hospitals NHS Trust</td>
<td>7</td>
<td>63.6</td>
<td>4</td>
<td>36.4</td>
<td>11</td>
</tr>
<tr>
<td>Hull and East Yorkshire Hospitals NHS Trust</td>
<td>7</td>
<td>77.8</td>
<td>2</td>
<td>22.2</td>
<td>9</td>
</tr>
<tr>
<td>Newcastle Upon Tyne Hospitals NHS Foundation Trust</td>
<td>39</td>
<td>92.9</td>
<td>3</td>
<td>7.1</td>
<td>42</td>
</tr>
<tr>
<td>North Cumbria Acute Hospitals NHS Trust</td>
<td>5</td>
<td>41.7</td>
<td>7</td>
<td>58.3</td>
<td>12</td>
</tr>
<tr>
<td>Nottingham University Hospitals NHS Trust</td>
<td>30</td>
<td>100.0</td>
<td>0</td>
<td>0.0</td>
<td>30</td>
</tr>
<tr>
<td>Poole Hospital NHS Foundation Trust</td>
<td>16</td>
<td>84.2</td>
<td>3</td>
<td>15.8</td>
<td>19</td>
</tr>
<tr>
<td>Royal Cornwall Hospitals NHS Trust</td>
<td>13</td>
<td>92.9</td>
<td>1</td>
<td>7.1</td>
<td>14</td>
</tr>
<tr>
<td>Royal Devon &amp; Exeter Healthcare NHS Foundation Trust</td>
<td>5</td>
<td>83.3</td>
<td>1</td>
<td>16.7</td>
<td>6</td>
</tr>
<tr>
<td>Royal Shrewsbury Hospital’s NHS Trust</td>
<td>11</td>
<td>84.6</td>
<td>2</td>
<td>15.4</td>
<td>13</td>
</tr>
<tr>
<td>Southend Hospital NHS Trust</td>
<td>12</td>
<td>100.0</td>
<td>0</td>
<td>0.0</td>
<td>12</td>
</tr>
<tr>
<td>Southern Derbyshire Acute Hospitals NHS Trust</td>
<td>27</td>
<td>84.4</td>
<td>5</td>
<td>15.6</td>
<td>32</td>
</tr>
<tr>
<td>South Devon Health Care NHS Foundation Trust</td>
<td>15</td>
<td>93.8</td>
<td>1</td>
<td>6.3</td>
<td>16</td>
</tr>
<tr>
<td>South Tees Acute Hospitals NHS Trust</td>
<td>19</td>
<td>100.0</td>
<td>0</td>
<td>0.0</td>
<td>19</td>
</tr>
<tr>
<td>University Hospitals of Leicester NHS Trust</td>
<td>16</td>
<td>80.0</td>
<td>4</td>
<td>20.0</td>
<td>20</td>
</tr>
<tr>
<td>University Hospital Birmingham NHS Foundation Trust</td>
<td>13</td>
<td>54.2</td>
<td>11</td>
<td>45.8</td>
<td>24</td>
</tr>
<tr>
<td>United Lincolnshire Hospitals NHS Trust</td>
<td>6</td>
<td>85.7</td>
<td>1</td>
<td>14.3</td>
<td>7</td>
</tr>
<tr>
<td>York Health Services NHS Trust</td>
<td>14</td>
<td>93.3</td>
<td>1</td>
<td>6.7</td>
<td>15</td>
</tr>
<tr>
<td>WELSH NETWORK</td>
<td>18</td>
<td>90.0</td>
<td>2</td>
<td>10.0</td>
<td>20</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>328</strong></td>
<td><strong>85.0</strong></td>
<td><strong>58</strong></td>
<td><strong>15.0</strong></td>
<td><strong>386</strong></td>
</tr>
</tbody>
</table>
Findings

Due to data quality issues, it has not been possible to produce a breakdown by trust, for those of the time from biopsy to reporting for oral cavity.

- To improve the patient pathway process mapping may identify areas where delays in the whole pathway could be reduced (from taking of a biopsy, through to its reporting).
- There are several methods of obtaining a biopsy in order to reach a diagnosis. The most appropriate method will be determined by the clinical presentation. This figure is a combination of data from cytological and histological specimens; these specimen types have different implications in terms of the complexity of interpretation and the types of diagnoses that can be made. Organisations should consider this complexity when reviewing pathways.
- Local MDTs should review regularly performance in the patient pathway.
- Manpower issues within pathology and in particular head and neck pathology remain a challenge.

Figure 8.5.5.1.c: Time from biopsy to reporting by trust, for those trusts reporting greater than 5 oral cavity cases
Findings

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

8.5.6.a Summated analysis of multi-disciplinary discussion for index year

Figure 8.5.6.a: The multi-disciplinary team (MDT) and its functions.

<table>
<thead>
<tr>
<th>Discussed</th>
<th>Larynx</th>
<th>Oral Cavity</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>71.6</td>
<td>76.9</td>
<td>74.2</td>
</tr>
<tr>
<td>No</td>
<td>6.6</td>
<td>4.9</td>
<td>5.8</td>
</tr>
<tr>
<td>Not recorded</td>
<td>21.8</td>
<td>18.2</td>
<td>20.1</td>
</tr>
</tbody>
</table>

- Overall 74 per cent of patients were confirmed as having been discussed at an MDT meeting. The expected standard (proposed in the SWAHN audit 1997-1999) suggested this should reach 100 per cent.

- It is a standard in the Improving Outcomes Guidance that all patients are discussed in an MDT.

- These results show that there has been a small increase in the number of patients whose management has been planned outside of an MDT. (3.8 per cent last year has risen to 5.8 per cent this year). Recorded as not discussed at MDT.

A number of providers have rates above the average and the project team will be alerting those organisations where high levels of not discussed are recorded to consider the reasons for this and to develop improvement plans.

- The Expert Panels considered whether the figures above were falsely low, as they were likely to contain some individuals who had not reached the point in the pathway for an MDT discussion to occur. A more detailed analysis of the cohort with a date of diagnosis before 1 October 2007, and those after this date was made.

- This showed little difference ie 75 per cent being recorded as having been discussed at an MDT in those with a date of diagnosis prior to 1 October 2007, whilst for those with a date of diagnosis after 1 October 2007 the rate of not recorded doubled and a significant fall in discussed occurred.

- The MDT is a key point of registration of a cancer diagnosis.

Good Practice Standard

100 per cent of diagnoses should be discussed at a MDT, currently in England and Wales only 74 per cent are recorded as having been discussed.

- The Expert Panels considered whether the figures reported above were a reflection on a number of organisations failing to record information, or partial recording across a wider range of providers.

- The chart below reports by provider the information supplied to the audit on MDT discussion. Care should be taken in assessing percentages where only small case numbers were submitted.
### 8.5.6.b Analysis of multi-disciplinary discussion for index year by provider trust

**Figure 8.5.6.b: Analysis of multi-disciplinary discussion for index year by provider trust**

<table>
<thead>
<tr>
<th>Hospital Trust</th>
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Findings

Larynx and Oral Cavity

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- 29 organisations who submitted over 10 cases to the audit discussed over 85 per cent of cases (unadjusted for dates of diagnosis after 1 October 2007) at MDT providing assurance of an aspect of their patient care and should be commended.

- 5 organisations who submitted over 10 diagnoses stated significant numbers of patients as not having being discussed at MDT. Cancer leads may wish to consider whether this reflects poor data quality or issues about the function and availability of the MDT. Whilst it is possible that for a small tumour, excision biopsy may be curative, it would still be expected that these cases would be discussed at MDT.

- Analysis by trust of MDT discussion will be a regular feature of future reports being a universally accepted best practice in head and neck cancer care.

**Good Practice Standard**

Patient expectations are that all care discussions are being made at a MDT, and head and neck cancer teams need to provide assurance around this important aspect of care delivery. 29 organisations have provided this.

### 8.5.7 Interval from diagnosis to decision to treat

#### 8.5.7.1 Interval from diagnosis to MDT (‘triage’ date)
Findings

• The median interval from diagnosis to MDT for larynx patients is 14 days and for oral cavity patients it is 18 days. Both of these times show a small decline from the first and second annual reports. Within the 62 day target for the two week wait referral to treatment (effective in England, from 1 January 2006) it would be expected that this interval may have reduced significantly.

• 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.

• 12 per cent of patients with laryngeal cancer and 20 per cent with oral cavity cancer have their MDT management planned in more than 30 days from the biopsy being taken. This may represent for oral cavity cancer a contribution from the delay to biopsy reporting seen in Figure 8.5.5.1.

• To examine whether there is variation in interval within organisations or variation in different providers the chart below compares those diagnoses where the interval from diagnosis is less than 30 days and those of 30 days or longer.
• In a minority of organisations all patients have an interval from diagnosis to MDT of less than 30 days, whilst in a quarter over 20 per cent of patients exceed 30 days.

• Local teams should regularly monitor patients’ pathway intervals and work with service improvement leads where regular delay is seen for both two week wait patients and those of other priorities.

The interval between diagnosis and treatment is critical for patients’ psychological response, especially the hope of a possible cure against the burden of the treatment process. Sensitive access of information by the health care team to patients may assist their response.

8.5.7.2 Interval from diagnosis to date care plan agreed

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

• It is an accepted standard that all patients are discussed in an MDT. 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.
Findings

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

- Where this information is recorded, in over 75 per cent of cases, primary care notification occurred on the same day. However, again only a 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 Number and percentage with histological confirmation prior to cancer careplan

- 1,815 patients can be associated with a diagnostic pathology date, and 1,575 of these patients have a careplan date (794 larynx, 781 oral cavity).

- Of these, 758 larynx (96 per cent) and 781 oral cavity (96 per cent) patients have histological confirmation recorded 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. It is encouraging to see that a major improvement in confirmation that histological confirmation is available ahead of a care plan (80 per cent previously) and the results seem likely due to a significant improvement in 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 Number and percentage with staging information recorded at time of cancer careplan

The percentage with staging information recorded at the 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.

1,685 patients have a careplan date (recorded entry in careplan agreed date, or recorded entry in management planned date) (860 Larynx, 825 Oral Cavity).

1,407 have some diagnostic T, N or M staging recorded (724 Larynx, 683 Oral Cavity)

The tables summarise those 1,685 records with a careplan date:

<table>
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<th>Larynx</th>
<th>Oral Cavity</th>
<th>Total</th>
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<tbody>
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<td>825</td>
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<table>
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<th>Oral Cavity</th>
<th>Total</th>
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<tr>
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<td>82.8</td>
<td>83.5</td>
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<td>No</td>
<td>15.8</td>
<td>17.2</td>
<td>16.5</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Good Practice Standard

The Expert Panels are unanimous that all MDTs must ensure the recording of accurate staging information in 100 per cent of patients.
Findings

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

- Imaging of the chest (by CXR or CT) is recorded in 536 patients of the 1,681 who have a careplan date.
- This appears to represent that only 32 percent of patients with a recorded careplan had chest imaging.
- Whilst the level of completeness superficially appears poor for this item, it needs to be recognised that on further discussion with a number of reporting centres (as preparation for reporting this item by named trust) there appeared a marked discrepancy between the frequency of chest imaging delivered and that reported. Where a combined CT of neck and thorax was performed the imaging of the thorax was not always recorded. Therefore results need to be interpreted with caution.
- This output was intended to reflect best practice where, due to the recognised incidence of second primary lung cancers, chest imaging should occur prior to a cancer careplan in all patients.
- Further training and consultation needs to occur to ensure accurate reflection of practice by this item.

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

Good Practice Standard

Synchronous malignancies of the chest can occur and have a significant impact on treatment options. Teams are encouraged to confirm that chest imaging has occurred in all head and neck cancer patients prior to planning treatment.
Progression of a patient along the cancer care pathway requires prompt imaging. Most of the 871 patients with recorded imaging had their imaging in less than 14 days from request. A much reduced (54 patients 2005-2006) but still relevant number of patients’ pathways, from the evidence collected, show delays. The figure below demonstrates the imaging requests where a delay greater than 4 weeks occurred.

However, a substantial number of organisations have not provided imaging data and therefore no firm conclusions can be made on the timeliness of imaging.

8.5.11.1 Imaging types where interval from imaging requests from data imaging is performed is 4 weeks or more

Figure 8.5.11.1.a: Imaging types where interval is 4 weeks or more

<table>
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<td>2</td>
<td>2</td>
</tr>
<tr>
<td>CT scan</td>
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</tr>
<tr>
<td>MRI scan</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
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<td><strong>Total</strong></td>
<td><strong>8</strong></td>
<td><strong>10</strong></td>
<td><strong>18</strong></td>
</tr>
</tbody>
</table>

In examining delays to CT/MRI scan this was found to apply to 7 organisations. Feedback will be provided in the local reports.

8.5.12 Interval from diagnosis to first definitive treatment

Figure 8.5.12.a: Larynx; Interval from diagnosis to first definitive treatment

- No delays to barium studies were found this year.
- Considerable effort has occurred in the NHS in England to reduce ‘delays to test’ and this has been studied by the Healthcare Commission. Cancer patients may have benefited from general improvements.
- A radiologist should be a core member of an MDT and this integration process should accelerate access to imaging.
- This information will continue to be looked at robustly in the future and organisations are encouraged to submit data to allow true comparison and assurance of timely pathways for patients.
Findings

- The majority of laryngeal cancer patients’ first treatment is primary radiotherapy, with a median interval of 45 days from the point of diagnosis. For the smaller number who undergo surgery the median interval from diagnosis to first recorded treatment is 25 days. These show little change.

- The majority of oral cavity cancer patient’s first treatment is surgery, with a median interval of 33 days from the point of diagnosis. For the smaller numbers who undergo primary radiotherapy, the median interval from diagnosis to first recorded treatment is 52 days.

- The results shown above, highlight that laryngeal and oral cavity cancer patients wait a similar interval for radiotherapy. The median time of 45 to 52 days is of concern for the ability to reach the 62 day target (England only).

- Also, of concern, is that 50 per cent of patients are waiting for more than 45 to 52 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 to treatment decision.

- Best practice suggests that primary radiotherapy should commence within 28 days of diagnosis.\(^{34,35}\)
### 8.5.12.1 Interval from diagnosis to first definitive treatment by trust and by type of treatment

The following chart examines by trust the interval from diagnosis to first definitive treatment and the intent of treatment. Only providers reporting to the audit 5 or more cases in a category are presented in order to assure patient confidentiality. Small numbers skew the pathway.

**Figure 8.5.12.1a: Interval from diagnosis to first definitive treatment by trust and by type of treatment (for those providers submitting 5 or more larynx cases).**

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<thead>
<tr>
<th>Treatment</th>
<th>Trust</th>
<th>Treatment intent</th>
<th>No. of cases</th>
<th>Min. No. days</th>
<th>Max. No. days</th>
<th>Median No. days</th>
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## Findings

### Larynx

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<th>Max. No. days</th>
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## Oral Cavity

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<th>Max. No. days</th>
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<td></td>
<td>South Tees Hospitals NHS Trust</td>
<td>Curative</td>
<td>11</td>
<td>0</td>
<td>105</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>Southend Hospital NHS Trust</td>
<td>Curative</td>
<td>12</td>
<td>10</td>
<td>71</td>
<td>32.5</td>
</tr>
<tr>
<td></td>
<td>Derby Hospitals NHS Foundation Trust</td>
<td>Curative</td>
<td>25</td>
<td>0</td>
<td>61</td>
<td>20</td>
</tr>
</tbody>
</table>

*Figure 8.5.12.1.b: Interval from diagnosis to first definitive treatment by trust and by type of treatment (for those providers submitting 5 or more oral cavity cases)*
### Oral Cavity

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Trust</th>
<th>Treatment intent</th>
<th>No. of cases</th>
<th>Min. No. days</th>
<th>Max. No. days</th>
<th>Median No. days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>All Hospitals</td>
<td>Curative</td>
<td>50</td>
<td>2</td>
<td>85</td>
<td>30.75</td>
</tr>
<tr>
<td>Surgery</td>
<td>Mid Yorkshire Hospitals NHS Trust</td>
<td>Not known</td>
<td>5</td>
<td>34</td>
<td>85</td>
<td>43</td>
</tr>
<tr>
<td>Surgery</td>
<td>Mid Essex Hospital Services NHS Trust</td>
<td>Not known</td>
<td>12</td>
<td>2</td>
<td>41</td>
<td>14.5</td>
</tr>
<tr>
<td>Surgery</td>
<td>Nottingham University Hospitals NHS Trust</td>
<td>Not known</td>
<td>21</td>
<td>12</td>
<td>47</td>
<td>30</td>
</tr>
<tr>
<td>Surgery</td>
<td>University Hospitals Coventry and Warwickshire NHS Trust</td>
<td>Not known</td>
<td>12</td>
<td>13</td>
<td>48</td>
<td>31.5</td>
</tr>
</tbody>
</table>

### Larynx

- For patients undergoing surgery with stated curative intent the median interval from diagnosis to first treatment was 25.5 days with a range from 0 to 114 days.

- For patients undergoing radiotherapy with curative intent was 46.5 days, with a range of 14 to 107.

### Oral cavity

- For patients undergoing surgery with stated curative intent the median interval from diagnosis to first treatment was 33.5 days with a range from 0 to 106 days.

- For patients undergoing radiotherapy with curative intent was 59.5 days, with a range of 31 to 161.

- The results demonstrate significant variation within organisations, but confirms the previously identified problem in accessing radiotherapy services.

- For surgery considerable variation is again seen, and MDTs should be encouraged to process map the pathway to minimise access times.

- MDTs may benefit from monitoring this interval prospectively between audits, and considering both patients on two week wait paths and those on non two week wait paths. The 31 day treatment target is from care plan agreed to start of definitive treatment but does not include the interval from diagnosis to care plan agreed.

- The fourth annual report will examine time intervals for treatment in recurrence.
8.5.13 Interval from referral to first definitive treatment in England

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

The 62 day target came into effect in England on 1 January 2006 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 69 days, but for two week wait patients it was 60 days.

- The median interval for oral cavity patients not referred via the two week rule was 54 days, but for two week wait patients it was 55 days.

- Whilst the median now falls less than 62 days for both larynx and oral cavity patients, considerable work remains to achieve this standard for all patients from date of referral to start of treatment. It should be noted that the intervals reported for two week rule patients are unadjusted (for cancellations, did not attend and deferred treatments etc).
8.5.14 Interval from surgical resection to reporting on resective specimen

The median interval to reporting for larynx is 8 days and oral cavity is 11 days.

In oral cavity, a consideration may be those specimens with composite bone resection which may require decalcification for complete assessment. In some circumstances it may be appropriate to consider issuing a preliminary report on the margins and neck status so that the further management of the patient can be decided without delay. Trusts should discuss with pathology colleagues if and when this approach might be possible, and also whether more rapid decalcification protocols could be introduced without sacrificing the quality of the final pathology report.

However, the curves for larynx and oral cavity are very similar suggesting that this may be a resource issue. Further work is required to define this part of the treatment pathway.
8.5.15 Interval from date of surgery to post-operative radiotherapy

The first recorded surgery date was considered. The first recorded radiotherapy after the surgery date was then compared to it, and the interval derived.

Figure 8.5.15.a: Interval from date of surgery to post-operative radiotherapy

- The median interval to post-operative radiotherapy was 56 days for larynx and 58 days for oral cavity. It should be noted the sample size is small.
- 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 6 weeks (42 days) to commencement of radiotherapy following surgery. 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.

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.
Findings

8.6 Care provided - squamous cell carcinoma larynx

- 1,049 cases of larynx cancer were registered onto the DAHNO application.
- 891 cases have a careplan of which 698 (78.3 per cent) of these cases have a careplan with recorded treatment. This indicates either recorded treatment or a recorded careplan indicating palliative or supportive care.

<table>
<thead>
<tr>
<th>First recorded treatment</th>
<th>Early stage</th>
<th>Late stage</th>
<th>Not staged*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>98</td>
<td>99</td>
<td>61</td>
<td>258</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>182</td>
<td>81</td>
<td>102</td>
<td>365</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>4</td>
<td>24</td>
<td>11</td>
<td>39</td>
</tr>
<tr>
<td>Chemoradiotherapy</td>
<td>4</td>
<td>16</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Not recorded</td>
<td></td>
<td></td>
<td></td>
<td>351</td>
</tr>
<tr>
<td>Total</td>
<td>288</td>
<td>225</td>
<td>185</td>
<td>1,049</td>
</tr>
</tbody>
</table>

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

- The data quality for this item has improved significantly.
- The established treatment for the majority of patients with laryngeal cancer in England and Wales is radiotherapy and this matches the results shown above.
- The previously noted increased number of early staged patients having received surgery as their first definitive treatment, matching to a rising popularity of endolaryngeal resection is not so evident with this years increased submission. Only one third of early laryngeal lesions were treated surgically.
- In advanced disease where appropriate, radical surgery (laryngectomy) with adjuvant radiotherapy is the curative treatment of choice. In those not suitable for surgery organ sparing protocols are being utilised.

8.6.1 Percentage having surgical resection with curative intent

- The intent was curative for 202 of the 255 cases with recorded surgery (79 per cent).
- Those with curative intent for surgery make up 29 per cent of the 698 with some recorded treatment, and 19.2 per cent of the total 1,049 cases.
- The 53 cases with intent other than curative show that: four are with palliative intent, 10 are with diagnostic intent, 12 are ‘not known’ and 25 have no intent recorded. 2 cases have incompatible codes from csv uploaded records.

8.6.2 Percentage by category of clearance for surgical resection margins

- Of the 202 records with curative intent, 58 per cent of records contained this information, a marked improvement in recording.
- In the 109 cases where laser excision of early lesions has occurred, a similar percentage had not had margins recorded (compared to open surgery) but as expected fewer cases had margins greater than 5 mm. Margins may be much narrower than for open surgery and thus obviate the classification used in data collection.
- Where open surgery was performed, one third of cases had margins over 1 mm clear, and a quarter more than 5 mm clear. However, the number not recorded obviates any significant conclusion.
8.6.3 Percentage having pre-treatment dental assessment

- A pre-treatment dental assessment is recorded for less than 6 per cent of the 1,049 larynx registrations (62 patients) and is a similar figure to last year (7 per cent). This is likely to reflect poor data quality.

- This is 9 per cent of the 688 cases with some record of treatment.

- An additional 64 larynx and oral cavity patients had a dental assessment but no date of treatment was recorded.

It is disappointing that the volume of data has not increased and MDTs are recommended to collect this data.

8.6.4 Percentage having pre-operative / pre-treatment speech and swallowing assessment (includes for 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 8 per cent of the 1,049 larynx registrations (81 patients).

- This is 12 per cent of the 688 cases with some record of treatment.

- The submission of this item has improved.

- 15 per cent of the 255 cases undergoing surgery.

- Of the 92 patients reported as having a laryngectomy, 35 (38 per cent) are recorded as having a speech and language assessment. It would be expected this would be over 80 per cent.

- A further 25 of those having a speech and swallowing assessment had this after treatment had commenced.

- Patient representatives feel it is imperative that speech and swallowing and dietetic support is available to all patients with laryngeal cancer from diagnosis. The lack of appropriate professional support should be seen as a priority requirement. For those undergoing laryngectomy the speech therapist plays an important role in supporting choice in the method of restored speech 59,60.

- An additional 50 larynx and oral cavity patients had a speech and language assessment but no date of treatment was recorded (18 larynx and 32 oral cavity).

The Expert Panel members would hope that this is not an accurate reflection of practice as it is extremely important to maintain good dental health throughout treatment 57,58.

Good Practice Standard

Dental health during and after treatment for head and neck cancer is a significant contributor to patient well being. MDTs are strongly encouraged to provide information to confirm that care is being provided.

Good Practice Standard

The absence of demonstration of appropriate speech and language support being provided to patients with laryngeal cancer remains a cause for concern, particularly in those undergoing laryngectomy.

Active involvement of speech and language colleagues in the audit process is to be encouraged by all MDTs.

- A pre-treatment dietetic assessment is recorded for 3 per cent of the 1,049 larynx registrations (27 patients) and is likely to reflect poor data quality.

- This is 4 per cent of the 688 cases with some record of treatment.

- Over 39 per cent of those having a dietetic assessment had this prior to treatment.

- 41 larynx patients had a post treatment dietetic assessment.
Good Practice Standard
Dietetic support is important through all parts of the patient pathway, particularly in those undergoing any form of treatment where the morbidity of the treatment can be reduced by appropriate support. MDTs are encouraged to confirm the dietetic care provided.

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 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 in all stages of laryngeal cancer.

Good Practice Standard
Phase II of DAHNO has extended sections on surgical voice restoration and dietetic information. It is hoped that active involvement of all health professionals who care for head and neck cancer patients will be encouraged by MDTs to provide a comprehensive record of the multi-professional care provided.

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

- 255 patients have at least one surgical procedure recorded.

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

<table>
<thead>
<tr>
<th>Larynx patients – surgery summary</th>
<th>Number</th>
<th>Percentage of 255 with surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Microlaryngeal resection</td>
<td>112</td>
<td>43.9</td>
</tr>
<tr>
<td>• of these 112 patients the number having neck dissection</td>
<td>0</td>
<td>36.1</td>
</tr>
<tr>
<td>Laryngectomy</td>
<td>92</td>
<td>11.7</td>
</tr>
<tr>
<td>• of these 92 the number having supraglottic laryngectomy</td>
<td>4</td>
<td>15.6</td>
</tr>
<tr>
<td>• of these 92, the number having neck dissection</td>
<td>11</td>
<td>12.1</td>
</tr>
<tr>
<td>• of these 92, number having primary surgical voice restoration</td>
<td>15</td>
<td>18.9</td>
</tr>
<tr>
<td>More extensive resection</td>
<td>8</td>
<td>3.1</td>
</tr>
<tr>
<td>Neck dissections (including those mentioned with laryngectomy and more extensive resection)*</td>
<td>66</td>
<td>25.9</td>
</tr>
<tr>
<td>Comprehensive neck dissection</td>
<td>31</td>
<td>12.2</td>
</tr>
<tr>
<td>Modified neck dissection</td>
<td>14</td>
<td>5.5</td>
</tr>
<tr>
<td>Selective neck dissection</td>
<td>27</td>
<td>10.6</td>
</tr>
</tbody>
</table>

*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 44 per cent of surgical procedures and its frequency is rising (compared to 39 per cent last year, and 30 per cent in 2004-2005) as an alternative to radical radiotherapy in early laryngeal cancer. The audit will continue to monitor this trend with interest.

• 36.1 per cent of surgical procedures were laryngectomies, with 95 per cent of these being total laryngectomies with only 17 per cent recorded as having primary surgical voice restoration. The expert panels felt again that this was not representative of current clinical practice.

• The Expert Panel members would expect that the majority of patients (in excess of 80 per cent) 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 full data collection above (Figure 8.6.5.a) limits the ability to resolve this.

• The fourth annual collection period includes an extensive section on surgical voice restoration which is hoped will encourage speech and language colleagues to more actively participate in the audit.

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

Good Practice Standard

It is important that all components of a surgical procedure are recorded to provide a true reflection of the breadth and complexity of surgical management. Surgical voice restoration appears currently under-represented in the surgical procedures submitted.

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 to the results shown above.

• 317 cases have recorded radical (curative or adjuvant) radiotherapy. This is 74 per cent of the 426 with recorded radiotherapy.

• Those with radical radiotherapy make up 62 per cent of the 688 with some recorded treatment, and 40.6 per cent of the total 1,049 cases.

• The 71 other cases with recorded radiotherapy break down as 14 with palliative intent and 67 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. Of the 32 patients having post surgical radiotherapy, 6 had undergone microlaryngeal resection, and 20 total laryngectomy. The former would suggest that margins at laser excision were close or incomplete and the latter could be influenced by both poor prognostic indicators in the primary specimen or neck.

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

• The availability of Radiotherapy Episode Statistics (RES) data from 2009, will be an opportunity for DAHNO to acquire radiotherapy data more readily.

8.6.7 Percentage having palliative treatment by type (ie 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.

• 21 patients have recorded palliative treatment, 2 per cent of the total 1,049 registrations, 3 per cent of the 688 with recorded treatment.

• The 21 cases break down as: 4 cases of palliative surgery, 14 cases of palliative radiotherapy and 4
cases with palliative chemotherapy. (one patient had two palliative radiotherapy treatments).

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

The previous view of the Expert Panel members, was that there was no available evidence supporting the notion that chemotherapy in isolation improves long term survival in laryngeal cancer. However, there has been renewed interest in organ preservation using chemotherapy with some evidence suggesting the benefits of concurrent chemoradiation and another, suggesting induction chemotherapy can be used to predict complete clinical responders. Again it will be of interest to assess the benefits as they accrue with time.

- The intent was curative, adjuvant or neo-adjuvant for 62 of the 85 cases with recorded chemotherapy (73 per cent).
- These 62 cases are 9 per cent of the 688 with some recorded treatment, and 8 per cent of the total 1,049 cases.
- The 62 cases with a chemotherapy record break down by intent as: 41 curative, 12 adjuvant, 9 neo-adjuvant and 4 palliative. 19 cases had unknown intent or were uncoded.
- A review where it appeared that patients had chemotherapy as sole treatment in laryngeal cancer, identified that the majority were given as part of a chemo radiotherapy regimen, but there were deficiencies in capturing the complete patient pathway.

8.6.9 Percentage referred to specialist palliative care team

There was only data in 10 cases of referral to a specialist palliative care team. Specialist palliative care practitioners 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 hospital organisations eg community and hospice care. The National Head and Neck Cancer Audit 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)

- 395 larynx cases have no recorded surgery, chemotherapy or radiotherapy.
- None of these cases have ‘supportive’ as their careplan intent.
- 14 of the other cases have ‘active monitoring’ as the careplan intent.

8.6.11 Percentage of patients where careplan agreed matches careplan delivered

- 891 of the 1,049 registrations have a recorded careplan (84.9 per cent).
- 532 of 891 patients have a treatment record matching the careplan (59.7 per cent), of which 559 careplans matched.
- Where the careplan was not matched the commonest occurrence was a proposed combined therapy, where only one of the treatments was recorded. This most likely reflects poor data quality but could reflect changes to planned management in surgery patients due to resective pathology findings or morbidity from therapy.
- MDTs are encouraged to record all treatments provided.

Note: Each patient can have more than one careplan. 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

- 986 cases of oral cavity cancer were registered onto the DAHNO application.
- 841 cases have a careplan of which 649 (77.1 per cent) of these cases have a careplan with recorded treatment. This indicates either recorded treatment or a recorded careplan indicating palliative or supportive care.

Note: 649 cases have been used as ‘the number of cases with recorded treatment’ in the calculation of percentages in this section.

Figure 8.7.a: Care provided – squamous cell carcinoma oral cavity

<table>
<thead>
<tr>
<th>First recorded treatment</th>
<th>Early stage</th>
<th>Late stage</th>
<th>Not staged*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>250</td>
<td>144</td>
<td>138</td>
<td>532</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>22</td>
<td>31</td>
<td>13</td>
<td>66</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>1</td>
<td>14</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Chemotherapy and radiotherapy (same day)</td>
<td>0</td>
<td>10</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>0</td>
<td>9</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Not recorded</td>
<td></td>
<td></td>
<td>337</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>273</strong></td>
<td><strong>208</strong></td>
<td><strong>168</strong></td>
<td><strong>986</strong></td>
</tr>
</tbody>
</table>

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

- The established treatment for the majority of patients with oral cavity cancer in England and Wales is primary surgery, and this matches the results shown above.
- Of the 649 with recorded treatment, 74 per cent have sufficient staging data to allow categorisation into early and late disease. Chemotherapy and chemoradiotherapy although in small numbers are almost exclusively found in the treatment of late stage disease.

8.7.1 Percentage having pre-treatment dental assessment

- A pre-treatment dental assessment is recorded for 20 per cent of the 841 oral cavity registrations with care plans (170 patients).
- This is 27 per cent of the 620 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.

8.7.2 Percentage having surgical resection with curative intent

- The intent was curative surgery for 441 of the 531 cases with recorded surgery (83 per cent).
- Those with curative surgery make up 71 per cent of the 620 with some recorded treatment, and 52 per cent of the total 841 cases with recorded care plans.
- The 90 cases with intent other than curative break down as; 1 with palliative intent, 9 with diagnostic intent, 1 with staging intent, 28 with intent not known and 51 with intent not recorded.

Good Practice Standard

Dental health, during and after treatment for head and neck cancer, is a significant contributor to patient well being. In oral cavity cancer proximity to the mandible or its direct involvement and the risks of ingress of infection following therapy, keep dental health as a high priority. MDTs are strongly encouraged to provide information to confirm that care is being provided.
8.7.3 Percentage by category of clearance for surgical resection margins

Percentages of 441 cases recorded as surgery with curative intent.

<table>
<thead>
<tr>
<th>Category</th>
<th>per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not recorded</td>
<td>38.3</td>
</tr>
<tr>
<td>1. Margin involved</td>
<td>6.1</td>
</tr>
<tr>
<td>2. &lt;1 mm clear</td>
<td>6.6</td>
</tr>
<tr>
<td>3. 1-5 mm clear</td>
<td>24.3</td>
</tr>
<tr>
<td>4. &gt; 5 mm clear</td>
<td>20.2</td>
</tr>
<tr>
<td>5. Uncertain</td>
<td>2.0</td>
</tr>
<tr>
<td>8. Not applicable</td>
<td>2.5</td>
</tr>
</tbody>
</table>

• Using the Royal College of Pathologists guidelines\(^{65}\), there was evidence in only 20 per cent of cases, of an acceptable clear margin.

• Only 58 per cent 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\(^{66,67}\).

• Of the records completed, a 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 13 per cent of the 841 oral cavity registrations with care plans (108 patients).

• This is 17 per cent of 634 cases with some record of treatment.

• Patients undergoing major surgery require extensive swallowing rehabilitation support.

• An additional 56 patients had speech and language assessment after the date of the first treatment.

Good Practice Standard

The absence of demonstration of appropriate speech and language and swallowing support, being provided to patients with oral cavity cancer, remains a cause for concern, particularly in those undergoing major surgery.

Active involvement of speech and language colleagues in the audit process is to be encouraged by all MDTs.

• A pre-treatment dietetic assessment is recorded for 6 per cent of the 841 oral cavity registrations with care plans (54 patients).

• This is 9 per cent of the 634 cases with some treatment.

• An additional 46 patients had a dietetic assessment after the date of the first treatment.

Good Practice Standard

Dietetic support is important through all parts of the patient pathway, particularly in those undergoing any form of treatment where the morbidity of the treatment can be reduced by appropriate support. MDTs are encouraged to confirm the dietetic care provided.

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 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)

<table>
<thead>
<tr>
<th>Oral cavity patients - surgery summary</th>
<th>Count</th>
<th>Percentage of 531 patients with surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Floor of mouth excision</td>
<td>79</td>
<td>14.9</td>
</tr>
<tr>
<td>of these 79, the number having neck dissection</td>
<td>39</td>
<td></td>
</tr>
<tr>
<td>Buccal mucosa excision</td>
<td>53</td>
<td>10.0</td>
</tr>
<tr>
<td>of these 53, the number having neck dissection</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Patients having tongue procedures</td>
<td>180</td>
<td></td>
</tr>
<tr>
<td>of these 180, the number having neck dissection</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>patients having total glossectomy</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>patients having partial glossectomy</td>
<td>107</td>
<td></td>
</tr>
<tr>
<td>patients having excision lesion of tongue</td>
<td>76</td>
<td></td>
</tr>
<tr>
<td>Patients having mandible procedures</td>
<td>84</td>
<td>15.8</td>
</tr>
<tr>
<td>of these 84, the number having neck dissection</td>
<td>62</td>
<td></td>
</tr>
<tr>
<td>patients having extensive mandibulectomy</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>patients having hemimandibulectomy</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>patients having marginal mandibulectomy</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>patients having mandibulectomy or excision lesion</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Total maxillectomy</td>
<td>2</td>
<td>0.4</td>
</tr>
<tr>
<td>Partial maxillectomy</td>
<td>23</td>
<td>4.3</td>
</tr>
<tr>
<td>Comprehensive neck dissection (includes those listed previously)</td>
<td>31</td>
<td>5.8</td>
</tr>
<tr>
<td>Modified neck dissection (includes those listed previously)</td>
<td>32</td>
<td>6.0</td>
</tr>
<tr>
<td>Selective neck dissection (includes those listed previously)</td>
<td>139</td>
<td>26.2</td>
</tr>
<tr>
<td>All neck dissections</td>
<td>210</td>
<td>39.5</td>
</tr>
<tr>
<td>Reconstruction mouth</td>
<td>94</td>
<td>17.7</td>
</tr>
<tr>
<td>with flap</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>with primary closure</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>with buccal flap</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>with pectoralis major</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>with radial forearm</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>With SSG</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Reconstruction mouth by cancer site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>tongue</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>lip</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>gum</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>mouth floor</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>palate</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>cheek mucosa</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>mouth vestibule</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>retromolar trigone</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Mouth unspecified</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>
Findings

- Surgery followed by adjuvant radiotherapy – determined by histological findings is the commonest 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.

- Of those patients undergoing floor of mouth excision only 50 per cent are recorded as having a neck dissection. The Expert Panels felt that this was a low figure compared to expected practice, but may reflect data quality issues.

- The number of reconstructions seems low, but may reflect that the method of data capture by multiple fields within the application, makes data capture difficult, and that the number of fields available is inadequate. A revision of the application has increased the number of procedural elements that can be recorded. Further review will be carried out in next year’s report. Surgical teams are encouraged to record all aspects of surgical care provided.

**Good Practice Standard**

It is important that all components of a surgical procedure are recorded to provide a true reflection of the breadth and complexity of surgical management.

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

- 102 cases have recorded radical (curative or adjuvant) radiotherapy. This is 74 per cent of the 137 cases with recorded radiotherapy.

- Those with radical radiotherapy make up 16 per cent of the 634 with some recorded treatment, and 10 per cent of the total 986 cases.

- 1 case of lateral border of tongue cancer was recorded as receiving brachytherapy.

- The 35 other cases with recorded radiotherapy break down as; 11 with palliative intent and 14 not known and 10 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 (ie radiotherapy, chemotherapy, surgery)

- 17 patients have recorded palliative treatment, 2 per cent of the total 986 registrations, 2.5 per cent of the 686 with recorded treatment.

- The 17 cases break down as: 1 case of palliative surgery, 11 cases of palliative radiotherapy and 6 cases with palliative chemotherapy (one patient had palliative chemoradiation).

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. There is, however, some evidence suggesting the benefits of concurrent chemoradiation, 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 32 of the 48 cases with recorded chemotherapy (67 per cent).
• These 48 cases are 7 per cent of the 686 with some recorded treatment, and 5 per cent of the total 986 cases.

• The 48 cases with a chemotherapy record breakdown by intent is; 19 curative, 7 neo-adjuvant, 6 adjuvant, 6 palliative and 7 with unknown intent and 3 not coded.

• A review where it appeared that patients had chemotherapy as sole treatment in oral cavity cancer, identified that the majority were given as part of chemo radiotherapy regimen, but there were deficiencies in capturing the complete patient pathway.

8.7.9 Percentage referred to specialist palliative care team

There was only data in 15 cases of referral to a specialist palliative care team.

Specialist palliative care practitioners 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 hospital organisations eg community and hospice care. The National Head and Neck Cancer Audit Team will be interested to hear about successful methodology to integrate this element of data capture from Cancer Networks.

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

• 340 oral cavity cases have no recorded surgery, chemotherapy or radiotherapy.

• None of these have ‘supportive’ as their careplan intent.

• 12 of the other cases have ‘active monitoring’ as their careplan intent.

8.7.11 Percentage of patients where careplan agreed matches careplan delivered

• 841 of the 986 registrations have a recorded careplan (85.3 per cent).

• 511 patients of 841 (representing 578 care plans) have a treatment record matching the careplan (61 per cent).

• Where the careplan was not matched the commonest occurrence was a proposed combined therapy, where only one of the treatments was recorded. This most likely reflects poor data quality but could reflect changes to planned management in surgery patients due to resective pathology findings or morbidity from therapy.

• MDTs are encouraged to record all treatments provided

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.

A case file was obtained from the Office for National Statistics of patients registered in the audit for which ONS had evidence of the registrant having died, from death certification. Of the 1,049 larynx cancers recorded 122 were deceased within 1 year of diagnosis. This includes deaths from all causes.

Of the 986 oral cavity registrants 134 had died within one year of diagnosis. One oral cavity patient was excluded with a date of death before a date of diagnosis. This includes deaths from all causes.

These deaths may be related to a number of causes such as aggressive disease or deaths from non cancer causes.

Revisiting those cases diagnosed in the second annual report, of the 742 laryngeal cancer patients 108 died within 1 year of diagnosis, and a further 51 (total 159) were deceased within 2 years of diagnosis.
Findings

Of the 692 oral cavity patients reported in the second annual report, 175 died within 1 year of diagnosis, with a further 69 deceased within 2 years of diagnosis (making a total of 244).

8.8.2 Locoregional recurrence within 1 year and 2 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 death within 30 days of surgery and / or within the same admission)

<table>
<thead>
<tr>
<th>Description</th>
<th>Larynx</th>
<th>Oral cavity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of reported deaths within 30 days of diagnosis, or with discharge destination 'death' after any admission</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Number of reported deaths within 30 days of surgery or with discharge destination 'death' after surgery</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Of these patients, the number whose death followed diagnostic surgery</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Of these patients, the number whose death followed recorded surgery with curative intent</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Of the others, number whose death followed recorded surgery with no treatment intent recorded</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total number of patients with recorded curative surgery</td>
<td>202</td>
<td>441</td>
</tr>
</tbody>
</table>

8.9 Clinical trials

Percentage entered into national clinical trials at cancer careplan has not been calculated.

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.

- 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.
- Further cycles of the audit will assist in providing nationally derived estimates of risk to patients and MDTs.
9.0 Future work

9.1 Phase II

The start of the fourth collection period coincided with the launch of Phase II of the National Head and Neck Cancer Audit which incorporates the following major changes:

- **Expansion of anatomical sites for which data collected**
- **Data on multiple pathologies now collected**
- **Move from UICC 5 – UICC 6 for staging (Effects T4 staging)**
- **Introduction of clinical nurse specialist (ClinNS), dietetic, swallowing and surgical voice reconstruction (SVR) dataset items**
- **Initial alignment with the Radiotherapy Episode Statistics (RES) dataset**
- **Incorporation of pathological staging**
- **Recording of radiological date of request and date of report**
- **Removal of Cancer Wait times (CWT) from the audit**

- **Anatomical subsites**
  Data is now being collected on malignant neoplasms in the oropharynx, hypopharynx and nasopharynx. Additionally malignancy of major salivary glands is now included.

- **New pathologies**
  In line with the change in anatomical sites being looked at we are now collecting data on a broader range of pathologies in the above sites in addition to squamous cell carcinoma of the oral cavity and larynx. A definitive list of salivary neoplasms is now included.

- **UICC 6**
  In order to better assess the likelihood of curative intent for treatments in advanced cancer we have moved to use UICC 6 which changes the way advanced tumours are characterised into T4a and T4b. This helps determine more accurately cases where radical treatment is more or less likely to be successful.

- **Clinical Nurse Specialist, dietetic, swallowing and SVR dataset items**
  The multimodality management of head and neck cancers means that to fully understand the processes of care and the involvement of key workers in the patient journey, data recording these interventions should be recorded. Additionally this will help identify areas where resource needs to be targeted to meet Improving Outcomes Guidance.

- **RES Dataset**
  The incorporation of several fields into DAHNO brings the audit into line with the Radiotherapy Episode Statistics dataset.

- **Pathological staging**
  Pathological staging is now incorporated and will help identify influences on outcomes as the audit matures.

- **Recording of radiological date of request and date of report**
  Recording of both the date of request for radiological imaging and date of report is now included, and will help define this part of the pathway more accurately.

- **Removal of Cancer Waiting Times from the audit**
  As Cancer Wait Times (CWT) data are collected by Trusts as a statutory requirement, the CWT fields have been removed from the National Head and Neck Cancer Audit.

9.2 Web DAHNO

A new supporting infrastructure was introduced in January 2008 using web based technology. Information detailing how users can access this system and supporting documentation can be found on the head and neck pages at www.ic.nhs.uk/canceraudits.

9.3 Casemix adjustment

The National Head and Neck Cancer Audit Project Team, in conjunction with the Data Management and Access Group are liaising with the Cancer Registries to utilise the currently reported cohort to develop a casemix adjustment model. The proposal is to use data from a pool of trusts with high levels of comprehensive data to examine the implications of casemix effects. This will be reported in the fourth annual report and if appropriate applied to outcome measures for next year’s analysis.
Appendix
Appendix 1

Project structure and membership

Project structure:

National Head and Neck Cancer Audit

Project Team

- **Remit:** Provides the overall direction for the service and manages the delivery of the audit. They manage the issues and risks as well as change requests, maintain the link to Secondary User Services (SUS) to develop the requirements and assist facilitation of migration, agree communication objectives and link to the Communication Team to ensure communication delivery. The Project Team is accountable for the success of the audit and is responsible for the management of all audit 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), Julie Michalowski-Project Manager, Steve Dean-Senior Project Manager (Cancer Audits), Clare Bailey-Project Support Officer, Ian Martin-Oral and Maxillofacial Surgeon-British Association of Head and Neck Oncologists, Patrick Bradley-Head and Neck Oncological Surgeon, Andrew Fishburn-British Association of Head and Neck Oncology Nurses, Mark Watson-British Association of Otolaryngology, Head and Neck Surgeons, Patrick Magennis-British Association of Oral and Maxillofacial Surgeons, Sarah Cameron-British Dietetic Association, Edward Odell-British Society for Oral and Maxillofacial Pathology, RD Errington-Clinical Oncology, Gerry Humphris-Clinical Psychology, Helen Laing-Healthcare Commission, 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, AJ Downes-Royal College of General Practitioners, JFC Olliff-Royal College of Radiologists, Tim Hellwell-Royal College of Pathologists, Jo Patterson-Royal College of Speech and Language Therapists, Professor Mike Richards-National Cancer Director-Cancer Action Team, Martin Old-NCASP Programme Manager

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 National Head and Neck 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), Julie Michalowski-Project Manager, Steve Dean-Senior Project Manager (Cancer Audits), Clare Bailey-Project Support Officer, Ian Martin-Oral and Maxillofacial Surgeon-British Association of Head and Neck Oncologists, Patrick Bradley-Head and Neck Oncological Surgeon, Andrew Fishburn-British Association of Head and Neck Oncology Nurses, Mark Watson-British Association of Otolaryngology, Head and Neck Surgeons, Patrick Magennis-British Association of Oral and Maxillofacial Surgeons, Sarah Cameron-British Dietetic Association, Edward Odell-British Society for Oral and Maxillofacial Pathology, RD Errington-Clinical Oncology, Gerry Humphris-Clinical Psychology, Helen Laing-Healthcare Commission, 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, AJ Downes-Royal College of General Practitioners, JFC Olliff-Royal College of Radiologists, Tim Hellwell-Royal College of Pathologists, Jo Patterson-Royal College of Speech and Language Therapists, Professor Mike Richards-National Cancer Director-Cancer Action Team, Martin Old-NCASP Programme Manager
Appendix 1

Data Management and Analysis Group

Remit: Manage requests for data received by the National Head and Neck Cancer Audit and the analysis of data collected as well as delivering the annual report and Provider Trust analysis reports and feedback

Accountable to: Head and Neck Clinical Reference Group

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), Julie Michalowski-Project Manager, Steve Dean-Senior Project Manager (Cancer Audits), Ronnie Brar-DAHNO Developer, Chris Carrigan-National Cancer Registration Coordinator, Henrik Møller-National Lead for Cancer Registries, Sandra Edwards-Cancer Intelligence Analyst, Patrick Bradley-Head and Neck Oncologic Surgeon, Christine Piil-CE Let's Face It charity, Jo Patterson-Macmillan Speech and Language Therapist, Patrick Magennis-Consultant Oral and Maxillofacial Surgeon, Ruth Jack-Cancer Registries, Sarah Cuthbertson-Trent Cancer Registry, Jason Poole-Trent Cancer Registry, Ceri White-Welsh Cancer Intelligence and Surveillance Unit, Simon Hodder-Welsh Clinical Representative, Clare Bailey-Project Support Officer

Expert Panel

Remit: 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, Mark Watson-ENT Surgeon, David Howard-ENT Surgeon, Martin Birchall ENT Surgeon and Professor of Surgery, Jon Hayter-Maxillofacial Surgeon, Cyrus Kerawala-Maxillofacial Surgeon, Simon Rogers-Maxillofacial Surgeon and Honorary Reader in OMFS, Chris Nutting-Consultant Oncologist and Hon. Senior Lecturer in Clinical Oncology, Simon Hodder-Maxillofacial Surgeon and Welsh Clinical Representative, Richard Wight-ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam-Maxillofacial Surgeon (Project Team Vice Chair), Julie Michalowski-Project Manager, Clare Bailey-Project Support Officer

User Groups

Remit: User representatives who participate in the National Head and Neck Cancer Audit that ensure the views of users are appropriately reflected in the audit

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 Provider Trust level nationwide

Meeting frequency: Quarterly

Membership: To be confirmed

Helpdesk

Remit: To respond to and manage technical and clinical queries from users and provide ad hoc training and support to networks and Provider Trusts

Accountable to: The Project Team

NCASP Team

NCASP Team including Programme Manager Martin Old and NCASP Communications Manager Charlotte Tye

Other Contributors

Jonathan Boyce and Dick Waite at the Healthcare Commission
Appendix 2

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
UK Association of Cancer Registries
Representatives from clinical oncology
Representatives from clinical psychology
Trent Cancer Registry
Welsh Cancer Intelligence and Surveillance Unit

Appendix 3

Technical infrastructure

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 4

Dataset and manual

Data collected in DAHNO strictly adheres to the National Cancer Dataset including the head and neck appendage (www.ic.nhs.uk/canceraudits).

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 for the first phase of the head and neck cancer audit.

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<tr>
<th>ID</th>
<th>Data Item</th>
</tr>
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<td>Clinical intervention date (cancer imaging) [Date of imaging]</td>
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<td>3.3</td>
<td>Cancer imaging modality [Imaging Modality]</td>
</tr>
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<td>3.4</td>
<td>Anatomical examination site [Anatomical Site Examined]</td>
</tr>
<tr>
<td>4.1</td>
<td>Diagnosis date (cancer) [Date of diagnosis]</td>
</tr>
<tr>
<td>4.2</td>
<td>Primary diagnosis (ICD) [Primary Site]</td>
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<tr>
<td>4.3</td>
<td>Tumour laterality [Laterality]</td>
</tr>
<tr>
<td>4.4</td>
<td>Basis of diagnosis (cancer) [Basis of diagnosis]</td>
</tr>
<tr>
<td>4.5</td>
<td>Histology (SNOMED) [Histology]</td>
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<td>5.1</td>
<td>MDT discussion indicator [Was this cancer care plan discussed at an MDT meeting?]</td>
</tr>
<tr>
<td>5.2</td>
<td>Multi-disciplinary team date [The date of the MDT meeting at which the cancer care plan was discussed]</td>
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<td>Careplan agreed date [Cancer care plan date]</td>
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<td>Cancer careplan intent [Cancer care plan intent]</td>
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<td>5.6</td>
<td>Planned cancer treatment type [Management modality]</td>
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<td>5.7</td>
<td>Treatment type sequence (cancer) [Treatment type sequence]</td>
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<td>5.9</td>
<td>Co-morbidity index for adults-ACE 27 [Co-morbidity index]</td>
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<td>5.10</td>
<td>Performance status (adult) [Performance status]</td>
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<td>6.1</td>
<td>T category (final pre-treatment) [Final pre-treatment T category]</td>
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<td>6.2</td>
<td>Staging certainty factor (T category) [Certainty factor for T category]</td>
</tr>
<tr>
<td>6.3</td>
<td>N Category (final pre-treatment) [Final pre-treatment N category]</td>
</tr>
<tr>
<td>6.4</td>
<td>Staging certainty factor (N category) [Certainty factor for N category]</td>
</tr>
<tr>
<td>6.5</td>
<td>M category (final pre-treatment) [Final pre-treatment M category]</td>
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<tr>
<td>6.6</td>
<td>Staging certainty factor (M category) [Certainty factor for M category]</td>
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<tr>
<td>6.7</td>
<td>TNM category (final pre-treatment) [Overall pre-treatment stage group]</td>
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<td>6.8</td>
<td>Staging certainty factor (TNM category) [Certainty factor for TNM stage]</td>
</tr>
<tr>
<td>6.10</td>
<td>TNM category (integrated) [Overall Pathological TNM stage grouping - integrated stage]</td>
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<td>6.11</td>
<td>T category (integrated stage) [Integrated stage - T category]</td>
</tr>
<tr>
<td>6.12</td>
<td>N category (integrated stage) [Integrated stage - N category]</td>
</tr>
<tr>
<td>6.13</td>
<td>M category (integrated stage) [Integrated stage - M category]</td>
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<td>7.4</td>
<td>Cancer treatment intent [Treatment intent]</td>
</tr>
<tr>
<td>7.5</td>
<td>Decision to treat (surgery) [Date of decision to operate]</td>
</tr>
<tr>
<td>7.9</td>
<td>Procedure date [Date of surgery]</td>
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<td>ID</td>
<td>Data Item</td>
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<td>-----</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>7.10</td>
<td>Primary procedure (OPCS) [Main surgical procedure]</td>
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<tr>
<td>7.11</td>
<td>Procedure (OPCS) [Sub-procedure]</td>
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<td>Discharge destination (hospital provider spell) [Discharge destination]</td>
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<td>Pathology Details</td>
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<td>8.1</td>
<td>Pathology investigation type [Report Type]</td>
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<td>8.3</td>
<td>Investigation result date [Date specimen reported]</td>
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<td>8.10</td>
<td>Histology (SNOMED) [Histology]</td>
</tr>
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<td>8.13</td>
<td>Excision margin [Excision Margins]</td>
</tr>
<tr>
<td>8.22</td>
<td>Specimen nature [Nature of specimen]</td>
</tr>
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<td>9</td>
<td>Chemotherapy and other drugs</td>
</tr>
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<td>9.4</td>
<td>Decision to treat date (Anti-cancer drug regimen) [Date of decision to treat with drug therapy]</td>
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<td>9.7</td>
<td>Drug therapy type [Drug therapy type]</td>
</tr>
<tr>
<td>9.8</td>
<td>Drug treatment intent [Treatment intent]</td>
</tr>
<tr>
<td>9.10</td>
<td>Start date (anti-cancer drug regimen) [Drug treatment start date]</td>
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<td>Radiotherapy (Teletherapy)</td>
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<td>10.3</td>
<td>Decision to treat date (teletherapy treatment course) [Date of decision to treat]</td>
</tr>
<tr>
<td>10.6</td>
<td>Cancer treatment intent [Treatment intent]</td>
</tr>
<tr>
<td>10.7</td>
<td>Radiotherapy anatomical treatment site [Anatomical treatment site]</td>
</tr>
<tr>
<td>10.8</td>
<td>Start course (teletherapy treatment course) [Teletherapy start date]</td>
</tr>
<tr>
<td>11</td>
<td>Radiotherapy (Brachytherapy)</td>
</tr>
<tr>
<td>11.3</td>
<td>Decision to treat date (Brachytherapy treatment course) [Date of decision to treat]</td>
</tr>
<tr>
<td>11.6</td>
<td>Cancer treatment intent [Treatment intent]</td>
</tr>
<tr>
<td>11.9</td>
<td>Start date (Brachytherapy treatment course) [Brachytherapy start date]</td>
</tr>
<tr>
<td>12</td>
<td>Palliative Care</td>
</tr>
<tr>
<td>12.1</td>
<td>Decision to treat date (specialist palliative treatment course) [Date of decision to treat]</td>
</tr>
<tr>
<td>12.2</td>
<td>Start date (specialist palliative treatment course) [Specialist Palliative Care start date]</td>
</tr>
<tr>
<td>13</td>
<td>Clinical Trials</td>
</tr>
<tr>
<td>13.1</td>
<td>Patient trial status (cancer) [Clinical trial status]</td>
</tr>
<tr>
<td>14</td>
<td>Clinical Status Assessment</td>
</tr>
<tr>
<td>14.1</td>
<td>Clinical status assessment date (cancer) [Date of contact]</td>
</tr>
<tr>
<td>14.2</td>
<td>Primary tumour status [Primary tumour status]</td>
</tr>
<tr>
<td>14.3</td>
<td>Nodal status [Nodal status]</td>
</tr>
<tr>
<td>14.4</td>
<td>Metastatic status [Metastatic status]</td>
</tr>
<tr>
<td>14.10</td>
<td>Morbidity code (chemotherapy) [Treatment related morbidity]</td>
</tr>
<tr>
<td>14.11</td>
<td>Morbidity code (radiotherapy) [Treatment related morbidity]</td>
</tr>
<tr>
<td>14.12</td>
<td>Morbidity code (combination) [Treatment related morbidity]</td>
</tr>
<tr>
<td>15</td>
<td>Death Details</td>
</tr>
<tr>
<td>15.1</td>
<td>Death date [Date of death]</td>
</tr>
</tbody>
</table>
Appendix 5

First priority outputs (larynx and oral cavity)

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

8.3.1 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 – eg cancer registries, HES data, pathology records etc.)

8.3.3 Submission, by network and provider trust, of patients with new head and neck primaries of the larynx and oral cavity.

8.4 Demography, casemix and socio economic status

8.4.1 Age and sex distributions

8.4.2 Distribution of Stage at point of treatment decision, and final definitive staging to include pathological TMN (pTMN) (including ‘C’ certainty factor relating to TNM stage and date of staging)

8.4.3 Distribution of Performance Status at point of treatment decision

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

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

8.5 Diagnostic and staging process, waiting times

8.5.1 Source of referral to specialist team (2ww v non 2ww)(primary v secondary )

8.5.3 Interval from first symptom to referral to specialist team

8.5.4 Time to first appointment from referral

8.5.5 Time to diagnosis from referral

8.5.5.1 Time from biopsy to its reporting

8.5.7 Time to decision to treat from diagnosis, expressed as :

8.5.7.1 Time to MDT (‘triage’ date) from diagnosis

8.5.7.2 Time to care plan date agreed from diagnosis

8.5.7.3 Time to sending communication to primary care from date care plan agreed

8.5.6 % discussed at MDT meeting

8.5.8 Number and % with histological confirmation prior to cancer care plan

8.5.9 Number and % with staging information recorded at time cancer care plan

8.5.10 % having chest imaging by CXR or CT prior to cancer care plan

8.5.11 Time from decision to make imaging request to reporting for imaging (CT/MRI) contributory to pre treatment staging complying with college guidelines

8.5.11.1 Imaging types where interval from imaging request to imaging performed is four weeks or more

8.5.12 Time to first definitive treatment from diagnosis

8.5.13 Time from referral to first definitive treatment in England

8.5.14 Time from surgical resection to histological reporting on resective specimen

8.5.15 Time from date of surgery to first treatment for post operative radiotherapy

8.6 Treatment: squamous cell carcinoma larynx (all sites) – recognising the need to record more than one treatment modality if applicable
Appendix 5

8.6.1 % having surgical resection with curative intent

8.6.2 % by category of clearance for surgical resection margins

8.6.3 % having pre treatment dental assessment

8.6.4 % having pre operative speech and swallowing assessment (includes for laser cordectomy)

8.6.4 % having pre operative/ pre treatment (includes radio and chemo therapy) dietetic assessment

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

8.6.6 % having radical radiotherapy (including post operative planned and unplanned)

8.6.7 % having palliative treatment by type (ie. radiotherapy, chemotherapy, surgery)

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

8.6.9 % referred to specialist palliative care team

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

8.6.11 % patients where care plan agreed matches care plan delivered

8.7 Treatment: squamous cell carcinoma oral cavity (all sites) – recognising the need to record more than one treatment modality if applicable

8.7.1 % having pre treatment dental assessment

8.7.2 % having surgical resection with curative intent

8.7.3 % by category of clearance for surgical resection margins

8.7.4 % having pre operative speech and swallowing assessment

8.7.4 % having pre operative/pre treatment dietetic assessment

8.7.5 % receiving each category of surgical procedure (including surgery to neck)

8.7.5 type of flap repair (if applicable)

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

8.7.7 % having palliative treatment by type (ie. radiotherapy, chemotherapy, surgery)

8.7.8 % having chemotherapy (including categories such as ‘adjuvant’ and ‘neo-adjuvant’)

8.7.9 % referred to specialist palliative care team

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

8.7.11 % patients where care plan agreed matches care plan delivered

8.8 Patient outcomes

8.8.1 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)

8.8.2 2 year survival

8.8.3 3 year survival

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

8.8.5 Loco regional recurrence within 1 year and 2 years of diagnosis (by treatment and tumour type- which will require recording of recurrence by type)

8.9 Clinical trials

8.9 % entered into National Clinical trials at cancer care plan – not calculated in 2007 report
Appendix 6

UICC 6 TMN Classification of Malignant Tumours

UICC International Union Against Cancer

Larynx

Supraglottis T – Primary Tumour

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 to larynx with vocal cord fixation and/or invades any of the following: postcricorid area, pre-epiglottic tissues, paraglottic space, and/or with minor thyroid cartilage erosion (e.g., inner cortex)
T4a  Tumour invades through the thyroid cartilage, or invades tissues beyond the larynx eg trachea, soft tissues of neck including deep/extrinsic muscle of tongue (genioglossus, hyoglossus, palatoglossus, and styloglossus), strap muscles, thyroid, oesophagus
T4b  Tumour invades prevertebral space, mediastinal structures, or encases carotid artery
TX  Primary tumour cannot be assessed

Glottis T – Primary Tumour

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)
T4a  Tumour invades through the thyroid cartilage, or invades tissues beyond the larynx eg trachea, soft tissues of neck including deep/extrinsic muscle of tongue (genioglossus, hyoglossus, palatoglossus, and styloglossus), strap muscles, thyroid, oesophagus
T4b  Tumour invades prevertebral space, mediastinal structures, or encases carotid artery
TX  Primary tumour cannot be assessed

Subglottis T – Primary Tumour

T1  Tumour limited to subglottis
T2  Tumour extends to vocal cord(s) with normal or impaired mobility
T3  Tumour limited to larynx with vocal cords fixation
T4a  Tumour invades through cricoid or thyroid cartilage and/or invades tissues beyond the larynx, eg, trachea, soft tissues of neck including deep/extrinsic muscle of tongue (genioglossus, hyoglossus, palatoglossus, and styloglossus), strap muscles, thyroid, oesophagus
T4b  Tumour invades prevertebral space, mediastinal structures, or encases carotid artery
TX  Primary tumour cannot be assessed

Larynx N – Regional Lymph Nodes

N0  No regional lymph node metastasis
Appendix 6

N1  Metastasis in a single ipsilateral lymph node, 3 cm or less in greatest dimension

N2  Metastasis in a single ipsilateral lymph node, more than 3 cm but not more than 6 cm in greatest dimension; or in multiple ipsilateral lymph nodes, none more than 6 cm in greatest dimension; or in bilateral or contralateral lymph nodes, none more than 6 cm in greatest dimension

N2a Metastasis in a single ipsilateral lymph nodes, none more than 3 cm but not more than 6 cm in greatest dimension

N2b Metastasis in multiple ipsilateral lymph nodes, none more than 6 cm in greatest dimension

N2c Metastasis in bilateral or contralateral lymph nodes, none more than 6 cm in greatest dimension

N3  Metastasis in a lymph node more than 6 cm in greatest dimension

NX  Regional lymph nodes cannot be assessed

M – Distant Metastasis

M0  No distant metastasis

M1  Distant metastasis

MX  Distant metastasis cannot be assessed

Stage Grouping (Larynx)

<table>
<thead>
<tr>
<th>Stage</th>
<th>T value</th>
<th>N value</th>
<th>M value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Tis</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage I</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage II</td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage III</td>
<td>T1, T2, T3</td>
<td>N1, N1</td>
<td>M0, M0</td>
</tr>
<tr>
<td></td>
<td>T4a</td>
<td>N2, N1, N2</td>
<td>M0, M0</td>
</tr>
<tr>
<td>Stage IVa</td>
<td>T4b</td>
<td>Any N</td>
<td>M0</td>
</tr>
<tr>
<td></td>
<td>Any T</td>
<td>Any N</td>
<td>M0</td>
</tr>
<tr>
<td>Stage IVb</td>
<td>Any T</td>
<td>Any N</td>
<td>M1</td>
</tr>
</tbody>
</table>

Oral Cavity T – Primary Tumour

T1  Tumour 2 cm or less in greatest dimension

T2  Tumour more than 2 cm but not more than 4 cm in greatest dimension

T3  Tumour more than 4 cm in greatest dimension

T4a Tumour invades through cortical bone, into deep/extrinsic muscle of tongue (genioglossus, hyoglossus, palatoglossus, and styloglossus), maxillary sinus, or skin of face

T4b Tumour invades masticator space, pterygoid plates, or skull base, or encases internal carotid artery

TX  Primary tumour cannot be assessed

Oral Cavity N – Regional Lymph Nodes

N0  No regional lymph node metastasis

N1  Metastasis in a single ipsilateral lymph node, 3 cm or less in greatest dimension

N2  Metastasis in a single ipsilateral lymph nodes, more than 3 cm but not more than 6 cm in greatest dimension; or in multiple ipsilateral lymph nodes, none more than 6 cm in greatest dimension; or in bilateral or contralateral lymph nodes, none more than 6 cm in greatest dimension

N2a Metastasis in a single ipsilateral lymph node, more than 3 cm but not more than 6 cm in greatest dimension

N2b Metastasis in multiple ipsilateral lymph nodes, none more than 6 cm in greatest dimension

N2c Metastasis in bilateral or contralateral lymph nodes, none more than 6 cm in greatest dimension

NX  Regional lymph nodes cannot be assessed
M – Distant Metastasis

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

Stage Grouping (Oral Cavity)

<table>
<thead>
<tr>
<th>Stage</th>
<th>T value</th>
<th>N value</th>
<th>M value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Tis</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage I</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage II</td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
</tr>
<tr>
<td>Stage III</td>
<td>T1, T2, T3</td>
<td>N1 N0, N1</td>
<td>M0 M0</td>
</tr>
<tr>
<td>Stage IVa</td>
<td>T1, T2, T3 T4a</td>
<td>N2 N0, N1 N2</td>
<td>M0 M0</td>
</tr>
<tr>
<td>Stage IVb</td>
<td>Any T T4b</td>
<td>N3 Any N</td>
<td>M0 M0</td>
</tr>
<tr>
<td>Stage IVc</td>
<td>Any T</td>
<td>Any N</td>
<td>M1</td>
</tr>
</tbody>
</table>
**Appendix 7**

**Adult Co-morbidity Evaluation (ACE-27)**

**UK Values**

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.

<table>
<thead>
<tr>
<th>Cogent comorbid ailment</th>
<th>Grade 3 Severe Decompensation</th>
<th>Grade 2 Moderate Decompensation</th>
<th>Grade 3 Mild Decompensation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular System</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myocardial Infarct</td>
<td>• MI &lt; 6 months</td>
<td>• MI &gt; 6 months ago</td>
<td>• Old MI by ECG only, age undetermined</td>
</tr>
<tr>
<td>Angina / Coronary Artery Disease</td>
<td>• Unstable angina</td>
<td>• Chronic exertional angina, Recent (&lt; 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty (PTCA), Recent (&lt; 6 months) coronary stent</td>
<td>• ECG or stress test evidence or catheterization evidence of coronary disease without symptoms, Angina pectoris not requiring hospitalization, CABG or PTCA (&gt; 6 months), Coronary stent (&gt; 6 months)</td>
</tr>
<tr>
<td>Congestive Heart Failure (CHF)</td>
<td>• Hospitalized for CHF within past 6 months, Ejection fraction &lt; 20%</td>
<td>• Hospitalized for CHF &gt;6 months prior, CHF with dyspnea which limits activities</td>
<td>• CHF with dyspnea which has responded to treatment, Exertional dyspnea, Paroxysmal Nocturnal Dyspnea (PND)</td>
</tr>
<tr>
<td>Arrhythmias</td>
<td>• Ventricular arrhythmia &lt; 6 months</td>
<td>• Ventricular arrhythmia &gt; 6 months, Chronic atrial fibrillation or flutter, Pacemaker</td>
<td>• Sick Sinus Syndrome</td>
</tr>
<tr>
<td>Hypertension</td>
<td>• DBP&gt;130 mm Hg, Severe malignant papilledema or other eye changes, Encephalopathy</td>
<td>• DBP 115-129 mm Hg, DBP 90-114 mm Hg while taking antihypertensive medications, Secondary cardiovascular symptoms: vertigo, epistaxis, headaches</td>
<td>• DBP 90-114 mm Hg while not taking antihypertensive medications, DBP &lt;90 mm Hg while taking antihypertensive medications, Hypertension, not otherwise specified</td>
</tr>
<tr>
<td>Venous Disease</td>
<td>• Recent PE (&lt; 6 months), Use of venous filter for PE's</td>
<td>• DVT controlled with Coumadin or heparin, Old PE &gt; 6 months</td>
<td>• Old DVT no longer treated with Coumadin or Heparin</td>
</tr>
<tr>
<td>Peripheral Arterial Disease</td>
<td>• Bypass or amputation for gangrene or arterial insufficiency &lt; 6 months ago, Untreated thoracic or abdominal aneurysm (&gt;6 cm)</td>
<td>• Bypass or amputation for gangrene or arterial insufficiency &gt; 6 months ago, Chronic insufficiency</td>
<td>• Intermittent claudication, Untreated thoracic or abdominal aneurysm (&lt; 6 cm), s/p abdominal or thoracic aortic aneurysm repair</td>
</tr>
</tbody>
</table>
### Appendix 7

<table>
<thead>
<tr>
<th><strong>Cogent comorbid ailment</strong></th>
<th><strong>Grade 3</strong></th>
<th><strong>Grade 2</strong></th>
<th><strong>Grade 3</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Respiratory System</strong></td>
<td>Severe Decompensation</td>
<td>Moderate Decompensation</td>
<td>Mild Decompensation</td>
</tr>
<tr>
<td>• Marked pulmonary insufficiency</td>
<td>• Restrictive Lung Disease or COPD with dyspnea at rest despite treatment</td>
<td>• Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities</td>
<td>• Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment</td>
</tr>
<tr>
<td>• Restrictive Lung Disease or COPD with dyspnea at rest despite treatment</td>
<td>• Chronic supplemetnal O2</td>
<td>• FEV1 (51%-65%)</td>
<td>• FEV1 (66%-80%)</td>
</tr>
<tr>
<td>• Chronic supplemetnal O2</td>
<td>• CO2 retention (pCO2 &gt; 6.7 kPa)</td>
<td>• Baseline pO2 &lt; 6.7 kPa</td>
<td>• Baseline pO2 &lt; 6.7 kPa</td>
</tr>
<tr>
<td>• Baseline pO2 &lt; 6.7 kPa</td>
<td>• FEV1 (&lt; 50%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Gastrointestinal System</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hepatic</strong></td>
</tr>
<tr>
<td>• Portal hypertension and/or esophageal bleeding &lt; 6 months (Encephalopathy, Ascites, Jaundice with Total Bilirubin &gt; 34mmol/l)</td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>End-stage renal disease</strong></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Creatinine &gt; 265 umol/l with multi-organ failure, shock, or sepsis</td>
<td>• Chronic Renal Insufficiency with creatinine &gt; 265 umol/l</td>
<td>• Chronic Renal Insufficiency with creatinine 177-265umol/l.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Chronic dialysis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Endocrine System</strong> (Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diabetes Mellitus</strong></td>
</tr>
<tr>
<td>• Hospitalization &lt; 6 months for DKA</td>
</tr>
<tr>
<td>• Diabetes causing end-organ failure</td>
</tr>
<tr>
<td>- retinopathy</td>
</tr>
<tr>
<td>- neuropathy</td>
</tr>
<tr>
<td>- nephropathy*</td>
</tr>
<tr>
<td>- coronary disease*</td>
</tr>
<tr>
<td>• peripheral arterial disease*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Neurological System</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stroke</strong></td>
</tr>
<tr>
<td>• Acute stroke with significant neurologic deficit</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Dementia</strong></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Severe dementia requiring full support for activities of daily living</td>
<td>• Moderate dementia (not completely self-sufficient, needs supervising)</td>
<td>• Mild dementia (can take care of self)</td>
<td></td>
</tr>
</tbody>
</table>

| **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 |
## Appendix 7

<table>
<thead>
<tr>
<th>Cogent comorbid ailment</th>
<th>Grade 3 (Severe Decompensation)</th>
<th>Grade 2 (Moderate Decompensation)</th>
<th>Grade 3 (Mild Decompensation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuromuscular</td>
<td>MS, Parkinson’s, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living</td>
<td>MS, Parkinson’s, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care</td>
<td>MS, Parkinson’s, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>Recent suicidal attempt, Active schizophrenia</td>
<td>Major depression or bipolar disorder uncontrolled, Schizophrenia controlled w/meds</td>
<td>Major depression or bipolar disorder controlled w/meds</td>
</tr>
<tr>
<td>Rheumatologic (incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)</td>
<td>Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)</td>
<td>Connective Tissue Disorder on steroids or immunosuppressant medications</td>
<td>Connective Tissue Disorder on NSAIDS or no treatment</td>
</tr>
<tr>
<td>Immunological System (AIDS should not be considered a co-morbidity for Kaposi’s Sarcoma or Non-Hodgkin’s Lymphoma)</td>
<td>Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)</td>
<td>HIV+ with h/o defining illness, CD4+ &lt; 200μL</td>
<td>Asymptomatic HIV+ patient, HIV+ w/o HIV defining illness, CD4+ &gt; 200μL</td>
</tr>
<tr>
<td>Malignancy (excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)</td>
<td>Uncontrolled cancer, Newly diagnosed but not yet treated, Metastatic solid tumor</td>
<td>Any controlled solid tumor without documented metastases, but initially diagnosed and treated within the last 5 years</td>
<td>Any controlled solid tumor without documented metastases, but initially diagnosed and treated &gt; 5 years ago</td>
</tr>
<tr>
<td>Leukemia and Myeloma</td>
<td>Relapse</td>
<td>1st remission or new dx &lt;1yr</td>
<td>H/o leukemia or myeloma with last Rx &gt; 1 yr prior</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>Relapse</td>
<td>1st remission or new dx &lt;1yr</td>
<td>H/o lymphoma w/ last Rx &gt; 1yr prior</td>
</tr>
<tr>
<td>Substance Abuse (must be accompanied by social, behavioral, or medical complications)</td>
<td>Delirium tremens</td>
<td>Active alcohol abuse with social, behavioral, or medical complications</td>
<td>H/o alcohol abuse but not presently drinking</td>
</tr>
<tr>
<td>Alcohol</td>
<td>Acute Withdrawal Syndrome</td>
<td>Active substance abuse with social, behavioral, or medical complications</td>
<td>H/o substance abuse but not presently using</td>
</tr>
<tr>
<td>Obesity</td>
<td>Morbid (i.e., BMI&gt;38)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**OVERALL CO-MORBIDITY SCORE (Circle one.)**

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
Appendix 8

Data Quality Trust Score Calculation

1. Measure of level of submission

Numbers of cases submitted overall versus index cases

2. Measure of Data Completeness

For all cases submitted measure of data completeness:

By 3 months from referral date, if have feature score

- Demographics 1
- Or Demographics and NHS number 2
- Referral event only 1
- Imaging event 1
- Diagnostic Pathology/Procedure event 1
- Diagnostic Summary with Site 1
- Care Plan only 1
- Or Care Plan and staging 2
- And Care Plan and at least one related treatment document 2

3. Convert to weighted score for Network/Trust.

This would need index cases by trust per year.

For Trusts providing diagnostics only:

Numbers submitted Within time period X 100 X Score =
Index cases 8

For Trusts providing diagnostics and treatment:

Numbers submitted Within time period X 100 X Score =
Index cases 10

4. Interpretation of weighted score

> 60 Very Good
26 – 59 Average
1 – 25 Poor
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>2WW</td>
<td>Two Week Wait</td>
</tr>
<tr>
<td>Adjuvant</td>
<td>a treatment given in concert with another to boost its activity</td>
</tr>
<tr>
<td>Aetiology</td>
<td>part of medical science dealing with the causes of disease</td>
</tr>
<tr>
<td>Alveolus</td>
<td>the portion of the jaw containing the teeth</td>
</tr>
<tr>
<td>Aspiration</td>
<td>withdrawal of fluids or gases from a cavity</td>
</tr>
<tr>
<td>BAHNO</td>
<td>British Association of Head and Neck Oncologists</td>
</tr>
<tr>
<td>Barium</td>
<td>a metallic element (in barium sulphate form) used in diagnostic imaging due to its propensity to absorb X-rays</td>
</tr>
<tr>
<td>Biopsy</td>
<td>removal and examination of tissue for diagnostic purposes</td>
</tr>
<tr>
<td>Brachytherapy</td>
<td>treatment modality using implantation of radioactive material</td>
</tr>
<tr>
<td>Buccal mucosa</td>
<td>mucous membrane of the mouth or inside of cheek</td>
</tr>
<tr>
<td>Cancer centre</td>
<td>specialised unit within a single or multiple hospitals that refers, diagnoses and treats cancer patients</td>
</tr>
<tr>
<td>Cancer site</td>
<td>area where cancer is located</td>
</tr>
<tr>
<td>CaNISC</td>
<td>Cancer Network Information System Cymru.</td>
</tr>
<tr>
<td>Careplan</td>
<td>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</td>
</tr>
<tr>
<td>Casemix</td>
<td>a means of classifying hospital patients to provide a common basis for comparing cost effectiveness and quality of care across hospitals.</td>
</tr>
<tr>
<td>CCAD</td>
<td>Central Cardiac Audit Database</td>
</tr>
<tr>
<td>CDS</td>
<td>Community Dental Service</td>
</tr>
<tr>
<td>CEU</td>
<td>Clinical Effectiveness Unit</td>
</tr>
<tr>
<td>CHART</td>
<td>continuous hyper fractionated accelerated radiotherapy</td>
</tr>
<tr>
<td>Chemoradiation</td>
<td>a combination of chemotherapy and radiotherapy</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>drugs used in the treatment of cancer</td>
</tr>
<tr>
<td>Child document</td>
<td>sub-document of a parent (top level) document</td>
</tr>
<tr>
<td>Co-morbidity</td>
<td>co existent illness(es) to the disease under consideration</td>
</tr>
<tr>
<td>Cordectomy</td>
<td>removal of the vocal chords</td>
</tr>
<tr>
<td>CSV</td>
<td>Comma Separated value</td>
</tr>
<tr>
<td>CT scan</td>
<td>computerised tomography scan - a radiological investigation</td>
</tr>
<tr>
<td>Curative</td>
<td>intending to cure</td>
</tr>
<tr>
<td>CXR</td>
<td>chest X-ray</td>
</tr>
<tr>
<td>Cytologist</td>
<td>medically qualified specialist in the study of cells and disease</td>
</tr>
<tr>
<td>Cytology</td>
<td>study of cells and disease</td>
</tr>
<tr>
<td>DAHNO</td>
<td>Data for Head and Neck Oncology</td>
</tr>
<tr>
<td>DAHNO application</td>
<td>software used to collate national, comparative head and neck cancer data</td>
</tr>
<tr>
<td>Dataset</td>
<td>collection of data items</td>
</tr>
<tr>
<td>Decompensation</td>
<td>the functional deterioration of a previously working structure or system. Decompensation may occur due to fatigue, stress, illness, or old age. When a system is “compensated”, it is able to function despite stressors or defects. Decompensation describes an inability to compensate for these deficiencies</td>
</tr>
<tr>
<td>Demographic</td>
<td>a statistic characterizing human populations (or segments of human populations) broken down by age or sex or income etc.</td>
</tr>
<tr>
<td>Deprivation</td>
<td>absence of expected level of social provision</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>DH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>confirming the presence of a disease</td>
</tr>
<tr>
<td>Dietician</td>
<td>Allied Health Professional specialising in aspects of nutrition</td>
</tr>
<tr>
<td>Dorsal</td>
<td>top surface</td>
</tr>
<tr>
<td>DSCN</td>
<td>Data Set Change Notification</td>
</tr>
<tr>
<td>Early adopter</td>
<td>team or individual taking up a new idea ahead of majority</td>
</tr>
<tr>
<td>Endolaryngeal</td>
<td>describing treatment of the larynx via a hollow endoscope</td>
</tr>
<tr>
<td>Endoscopy</td>
<td>visualisation of hollow organs</td>
</tr>
<tr>
<td>ENT</td>
<td>Ear, Nose and Throat</td>
</tr>
<tr>
<td>Epidemiologist</td>
<td>specialist in the study of prevalence of disease</td>
</tr>
<tr>
<td>Excision</td>
<td>removal of an area of tissue</td>
</tr>
<tr>
<td>Extensive resection</td>
<td>extension of surgical procedure to remove greater volume of tissue than normally required for named procedure</td>
</tr>
<tr>
<td>Flap repair</td>
<td>reconstructive surgery utilising a flap of tissue</td>
</tr>
<tr>
<td>GDP</td>
<td>General Dental Practitioner</td>
</tr>
<tr>
<td>Gingiva</td>
<td>mucosal tissue between and around teeth</td>
</tr>
<tr>
<td>Glossectomy</td>
<td>removal of the tongue</td>
</tr>
<tr>
<td>Glottis</td>
<td>the vocal apparatus of the larynx; the true vocal folds and the space between them where the voice tone is generated</td>
</tr>
<tr>
<td>GMP</td>
<td>General Medical Practitioner</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Healthcare Commission</td>
<td>an independent body, to promote and drive improvement in the quality of healthcare and public health in England and Wales.</td>
</tr>
<tr>
<td>Hemimandibulectomy</td>
<td>removal of half the mandible</td>
</tr>
<tr>
<td>Histology</td>
<td>microscopic study of cells and tissues</td>
</tr>
<tr>
<td>Histopathologist</td>
<td>medically qualified specialist in histology and pathology</td>
</tr>
<tr>
<td>HNCRG</td>
<td>Head and Neck Clinical Reference Group</td>
</tr>
<tr>
<td>Homogeneous</td>
<td>of similar consistency</td>
</tr>
<tr>
<td>Hypopharynx</td>
<td>the lowest section of the pharynx</td>
</tr>
<tr>
<td>IBM Lotus Domino®</td>
<td>the server architecture upon which the central DAHNO application database replica resides</td>
</tr>
<tr>
<td>IBM Lotus Notes®</td>
<td>the client software that renders the functionality of the DAHNO database to its users</td>
</tr>
<tr>
<td>IC</td>
<td>The Information Centre for health and social care (NHS body)</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases version 10 (a coding nomenclature prepared by the World Health Organisation).</td>
</tr>
<tr>
<td>IMD</td>
<td>Index of Multiple Deprivation</td>
</tr>
<tr>
<td>IOG</td>
<td>Improving Outcomes Guidance - issued by NICE</td>
</tr>
<tr>
<td>ISB</td>
<td>Information Standards Board</td>
</tr>
<tr>
<td>Laryngeal</td>
<td>of the larynx</td>
</tr>
<tr>
<td>Laryngectomy</td>
<td>removal of larynx (voice box)</td>
</tr>
<tr>
<td>Larynx</td>
<td>voice box - anatomic cartilage and soft tissue structure</td>
</tr>
<tr>
<td>LDP</td>
<td>local delivery plans</td>
</tr>
<tr>
<td>Lesion</td>
<td>abnormal area of tissue</td>
</tr>
<tr>
<td>Linear accelerator</td>
<td>radiotherapy machine to deliver high energy beam to treat cancer</td>
</tr>
<tr>
<td>Locoregional</td>
<td>area surrounding tumour and its expected lymph node drainage</td>
</tr>
<tr>
<td>Lymph node</td>
<td>a bean shaped focus of lymphoid tissue present in many areas of the body forming part of the immune system</td>
</tr>
<tr>
<td><strong>Glossary</strong></td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td></td>
</tr>
<tr>
<td><strong>Malignant</strong></td>
<td>cancerous</td>
</tr>
<tr>
<td><strong>Mandibulectomy</strong></td>
<td>removal of mandible</td>
</tr>
<tr>
<td><strong>Mandibulotomy</strong></td>
<td>division of mandible - usually for surgical access</td>
</tr>
<tr>
<td><strong>Maxillectomy</strong></td>
<td>removal of maxilla</td>
</tr>
<tr>
<td><strong>Maxillofacial</strong></td>
<td>of the face and jaws</td>
</tr>
<tr>
<td><strong>MDT</strong></td>
<td>Multi Disciplinary Team – a team of clinical specialists assembled to discuss and agree the appropriate care for a patient</td>
</tr>
<tr>
<td><strong>Meta analysis</strong></td>
<td>statistical technique to summate separate statistical analyses</td>
</tr>
<tr>
<td><strong>Metastasis</strong></td>
<td>distant spread of tumour</td>
</tr>
<tr>
<td><strong>MRI scan</strong></td>
<td>Magnetic Resonance Imaging – a scanning technique using magnetic and radio-waves</td>
</tr>
<tr>
<td><strong>Mucosa</strong></td>
<td>mucous membrane</td>
</tr>
<tr>
<td><strong>Multimodality</strong></td>
<td>combination of treatments</td>
</tr>
<tr>
<td><strong>NCASP</strong></td>
<td>National Clinical Audit Support Programme</td>
</tr>
<tr>
<td><strong>NCDS</strong></td>
<td>National Cancer Dataset – the standardised set of data items used in the collection of cancer data</td>
</tr>
<tr>
<td><strong>Neo-adjuvant</strong></td>
<td>a substance given ahead of another treatment to boost its effect</td>
</tr>
<tr>
<td><strong>Neoplasm</strong></td>
<td>new growth of tissue in part of body</td>
</tr>
<tr>
<td><strong>NHSIA</strong></td>
<td>NHS Information Authority – the name of the NHS body now known as ‘The Information Centre’</td>
</tr>
<tr>
<td><strong>NICE</strong></td>
<td>National Institute for Clinical Excellence - an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health</td>
</tr>
<tr>
<td><strong>NOS</strong></td>
<td>Not Otherwise Specified</td>
</tr>
<tr>
<td><strong>NSF</strong></td>
<td>National Service Framework – Dept. of Health long term strategies for improving specific areas of care. They set measurable goals within set time frames.</td>
</tr>
<tr>
<td><strong>Oncologists</strong></td>
<td>medically qualified non surgical specialists in cancer management</td>
</tr>
<tr>
<td><strong>ONS</strong></td>
<td>Office for National Statistics</td>
</tr>
<tr>
<td><strong>Oral cavity</strong></td>
<td>the mouth: anatomic area bounded by the lips palate and pharynx</td>
</tr>
<tr>
<td><strong>Oropharyngeal</strong></td>
<td>anatomical subsite the oropharynx e.g. a tumour arising in the oropharynx</td>
</tr>
<tr>
<td><strong>Osteoradionecrosis</strong></td>
<td>breakdown of bone as a consequence of previous radiotherapy</td>
</tr>
<tr>
<td><strong>Palate</strong></td>
<td>‘roof of the mouth’ comprising bony anterior portion and soft tissue portion posteriorly</td>
</tr>
<tr>
<td><strong>Palliative care</strong></td>
<td>care to alleviate a disease without intent of cure</td>
</tr>
<tr>
<td><strong>Parent document</strong></td>
<td>top level document that has subdocuments beneath it</td>
</tr>
<tr>
<td><strong>PAS</strong></td>
<td>Patient Administration System</td>
</tr>
<tr>
<td><strong>Pathology</strong></td>
<td>study of organs of the body in disease</td>
</tr>
<tr>
<td><strong>Pathway</strong></td>
<td>describes stages in the journey of care for a disease</td>
</tr>
<tr>
<td><strong>PCT</strong></td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td><strong>PET scan</strong></td>
<td>Positron Emission Tomography - a nuclear medicine technique which produces a three-dimensional image or map of functional processes in the body.</td>
</tr>
<tr>
<td><strong>Pharynx</strong></td>
<td>anatomical area from back of nose to start of oesophagus (gullet)</td>
</tr>
<tr>
<td><strong>PIAG</strong></td>
<td>Patient Information Advisory Group - PIAG was established to provide advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001. Its membership is drawn from patient groups, healthcare professionals and regulatory bodies.</td>
</tr>
<tr>
<td><strong>Prognosis</strong></td>
<td>predicted outcome of a disease</td>
</tr>
<tr>
<td><strong>Radiologist</strong></td>
<td>medically qualified imaging specialist</td>
</tr>
<tr>
<td><strong>Radiotherapy (RT)</strong></td>
<td>cancer treatment using high energy beams</td>
</tr>
<tr>
<td><strong>Glossary</strong></td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td><strong>RCT</strong></td>
<td>Randomised Control Trial - the essential characteristics of a RCT are that there will be a comparison between a treatment and placebo group. Great care is taken to avoid bias when collecting the data and assigning subjects (randomly) to their respective groups.</td>
</tr>
<tr>
<td><strong>Resective pathology</strong></td>
<td>pathology of a surgically removed specimen</td>
</tr>
<tr>
<td><strong>Retromolar area</strong></td>
<td>the area directly behind the molar teeth</td>
</tr>
<tr>
<td><strong>SALT</strong></td>
<td>Speech and Language Therapists</td>
</tr>
<tr>
<td><strong>Squamous cell carcinoma (SCC)</strong></td>
<td>the commonest cancer of mucous membranes in the head and neck</td>
</tr>
<tr>
<td><strong>Stage certainty</strong></td>
<td>validation of diagnostic method used to derive stage of cancer</td>
</tr>
<tr>
<td><strong>Subglottis</strong></td>
<td>area of voice box below vocal cords</td>
</tr>
<tr>
<td><strong>Supraglottis</strong></td>
<td>upper portion of voice box above vocal cords</td>
</tr>
<tr>
<td><strong>SUS</strong></td>
<td>Secondary Uses Services</td>
</tr>
<tr>
<td><strong>Surgeon</strong></td>
<td>medically qualified specialist who performs diagnostic assessments and operative procedures</td>
</tr>
<tr>
<td><strong>SWAHN</strong></td>
<td>South West Audit of Head and Neck Cancer</td>
</tr>
<tr>
<td><strong>Teletherapy</strong></td>
<td>high energy external beam used in the treatment of cancer</td>
</tr>
<tr>
<td><strong>Thorax</strong></td>
<td>chest cavity</td>
</tr>
<tr>
<td><strong>TNM</strong></td>
<td>Tumour, Node, Metastasis. Clinical Classification of anatomical extent of cancer</td>
</tr>
<tr>
<td><strong>Tomography</strong></td>
<td>multiple slice x-ray</td>
</tr>
<tr>
<td><strong>Triage</strong></td>
<td>preliminary assessment to determine future pathway of care</td>
</tr>
<tr>
<td><strong>Tuberculosis</strong></td>
<td>infectious granulomatous disease</td>
</tr>
<tr>
<td><strong>Tumour</strong></td>
<td>swelling or abnormal growth</td>
</tr>
<tr>
<td><strong>Voice Restoration</strong></td>
<td>means of achieving voice in a patient who has had a laryngectomy</td>
</tr>
<tr>
<td><strong>UICC</strong></td>
<td>International Union Against Cancer (French Acronym - Union Internationale Contre le Cancer)</td>
</tr>
<tr>
<td><strong>Ulceration</strong></td>
<td>erosion of a mucosal lining</td>
</tr>
<tr>
<td><strong>Ultrasonography</strong></td>
<td>technique of high frequency sound scans to visualise body structures</td>
</tr>
<tr>
<td><strong>Upper aero- digestive tract</strong></td>
<td>anatomic area from nose and mouth to start of gullet, includes both respiratory passages (nose and voice box) as well as mouth and pharynx</td>
</tr>
</tbody>
</table>
References


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