NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Head and neck cancer

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for head and neck cancer. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development sources below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development sources referenced in this briefing paper are:

- Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over (2016) NICE guideline 36.
- Improving outcomes in head and neck cancers (2004) NICE guideline CSG6. In June 2015 it was decided that this guideline should not be updated and the guidance was transferred to the static list.

2 Overview

2.1 Focus of quality standard

This quality standard will cover the assessment, diagnosis and management of head and neck cancer in all age groups. It will not cover cancer of the skin or brain.

2.2 Definition

Head and neck cancers are cancers of the mouth (oral cavity), voice box (larynx), throat / upper gullet (pharynx), salivary glands, nose, sinuses and middle ear, and primary bone tumours of the jaw.[1] Over 90 per cent of all malignant head and neck tumours are squamous cell carcinomas (SCC).

[1] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC

2.3 Incidence and prevalence

Head and neck cancer accounts for approximately 9,200 new cases diagnosed in England and Wales each year.

Between 1 November 2013 and 31 October 2014 8,429 diagnosed cases of head and neck cancer in England and Wales were reported to the national head and neck cancer audit[2]. This represented 92% of the estimated total case number. These comprised 2,684 oral cavity cancers, 2,439 oropharyngeal cancers, 1,763 laryngeal cancers, 504 major salivary gland cancers, 423 hypopharyngeal cancers, 335 nasal cavity and sinus cancers, 151 nasopharyngeal cancers and 130 bone tumours (mandible and maxilla).

2.4 Causes and Management

Head and neck cancer risk is greater in people who currently smoke[3], or have ever smoked in the past, than in those who have never smoked. The risk of head and neck cancer increases with the duration and frequency of cigarette smoking.

Excessive alcohol consumption is associated with increased risk of cancers of the oral cavity, hypopharynx, oropharynx and larynx. Compared to non-drinkers or occasional drinkers, laryngeal cancer risk is 1.4 times greater in people who drink 1.5–6 units of alcohol per day and 2.6 times greater in people who drink 6 units or more of alcohol per day.

Human papillomavirus (HPV) infection is associated with head and neck cancer, with the proportion of HPV-positive cancers varying by tumour subsite. The overall prevalence of HPV infection in head and neck cancers is between 22.0 and 26.0% Infection rates are highest for the oropharynx with HPV prevalence in oropharynx cancer estimated to be 35.6 to 47.7%.

The majority of nasopharyngeal cancers are associated with Epstein-Barr virus (EBV); it is estimated that 90% of cases in the UK are EBV-infected.

The disease burden of head and neck cancer is significant[4]. Patients require intensive multimodality treatments including surgery, chemotherapy and radiotherapy with or without concomitant chemotherapy and prolonged rehabilitation/ long-term support to achieve an adequate recovery. The disease significantly impacts on eating, drinking, voice, swallowing, smell, breathing, appearance, social interaction and work capabilities. Head and neck cancers have significant mortality. Prognosis is

[2] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC
[3] Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over, NICE 2016 full guideline
[4] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC

improved in early detection, while late presentation and neck node metastasis drastically reduce long term survival.

See appendix 2 for the associated care pathway from NICE clinical guideline 36.

2.5 National Outcome Frameworks

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS Outcomes Framework 2016–17

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults ii Children and young people 1b Life expectancy at 75 i Males ii Females ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer* i One- and ii Five-year survival from all cancers *v One- and vi Five-year survival from cancers diagnosed at stage 1 & 2*** **Reducing mortality in children** 1.6 i Infant mortality* iii Five-year survival from all cancers in children
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *ii Hospital care* ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving children and young people's experience of healthcare** *4.8 Children and young people's experience of inpatient services* **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 Public health outcomes framework for England 2016–19

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.19 Cancer diagnosed at stage 1 and 2*

4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.05 Under 75 mortality rate from cancer*
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

3 Summary of suggestions

3.1 Responses

In total 11 stakeholders and 5 specialist committee members responded to the 2-week engagement exercise 20/05/16 – 03/06/16.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 4 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Investigation • MDT • Systemic staging • FDG PET CT to detect primary site • FDG PET CT for detection of residual disease	SCM1, SCM2, SCM3, ENT UK, RD-UK
Treatment of early disease • Sentinel lymph node biopsy • Patient choice of surgery or radiotherapy • Access to comprehensive surgical reconstruction • Trans-oral robotic surgery (TORS)	SCM2, SCM3, SCM4, SCM5, NHSE, Norgine, ENT UK

Suggested area for improvement	Stakeholders
Optimising rehabilitation and function • Dental rehabilitation • Enteral nutrition support • Best supportive care • Timely rehabilitation • Community rehabilitation	RCSLT, SCM2, SCM3, ENT UK, RD-UK, RCR
Information and support • Information • Named clinical nurse specialist (CNS)	SCM3, SCM5
Additional areas • HIV • 2 week suspected cancer referral / detection and diagnosis • Shared decision making and information • Public awareness	BHIVA, ENT UK, SCM4, MSD, RCSLT
BHIVA, British HIV Association ENT UK MSD, Merck Sharp & Dohme NHSE, NHS England NOR, Norgine RCN, Royal College of Nursing RCPCH, Royal College of Paediatrics and Child Health RCR, Royal College of Radiologists RCSLT, Royal College of Speech & Language Therapists RD-UK, Association of Consultants and Specialists in Restorative Dentistry SCR, Society and College of Radiographers SCM, Specialist Committee Member	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 770 papers were identified for head and neck cancer. In addition, 39 papers were suggested by stakeholders at topic engagement and 11 papers internally at project scoping and through citation searching.

Of these papers, 4 have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

4 Suggested improvement areas

4.1 Investigation

4.1.1 Summary of suggestions

MDT

Stakeholders commented that restorative dentistry is very poorly represented in MDTs across the country. Head and neck cancer treatment can have long-term oral and dental side effects including very limited mouth opening, dry mouth, widespread destructive dental decay and problems with bone healing. These problems can be minimised by having the appropriate clinical staff available involved from the point of diagnosis and throughout the patient journey. The restorative specialist is the only dentist who has this comprehensive set of skills and the specific training to be able to carry out complex oral rehabilitation.

A stakeholder commented that many MDTs have limited access to non-specialist dieticians and speech and language therapists. Head and neck patients have specific pre and post treatment dietary and swallowing issues as well as communication problems, which need the input of more focused and specialised allied health professionals.

Systemic staging

A stakeholder suggested offering fluorodeoxyglucose positron emission tomography (FDG PET) CT to people with T4 cancer of the hypopharynx or nasopharynx and to people with N3 cancer of the upper aerodigestive tract. This could lead to more accurate systemic staging, more appropriate treatment and can identify those patients best served by a palliative approach.

FDG PET- CT to detect primary site

Stakeholders highlighted that FDG PET-CT should be considered as the first investigation to detect the primary site in people with metastatic nodal squamous cell carcinoma of unknown origin that is thought to arise from the upper aerodigestive tract. Identification of the primary tumour is important to guide treatment planning and follow-up.

Using FDG PET-CT scan as the first investigation to detect the primary site can lead to earlier detection of primary tumours with minimal burden of testing for the patient. It can also result in detection of a higher proportion of primary tumours and potentially reduced treatment related morbidity as a result of more targeted treatment.

FDG PET-CT for detection of residual disease

A stakeholder suggested the use of FDG PET-CT to detect residual disease in people with advanced upper aerodigestive tract cancer treated with chemoradiotherapy. This will lead to a reduction in number of people with this condition having unnecessary neck dissection.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
MDT	**Management by multi-disciplinary teams (MDTs)** NICE CSG6 Recommendation 2 **Access to specific services – Dental services** NICE CSG6 Recommendation 2
Systemic staging	**Clinical staging – who and how?** NICE NG36 Recommendations 1.2.9 and 1.2.10
FDG PET-CT to detect primary site	**Identifying the occult primary** NICE NG36 Recommendation 1.2.3
FDG PET-CT for detection of residual disease	Not directly covered in NICE NG36 and no recommendations are presented

MDT

Management by multi-disciplinary teams (MDTs)

NICE CSG6 – Recommendation 2

Members required for an MDT responsible for the management of UAT cancers are listed below.

- Restorative dentist.
- Speech and language therapist.
- Dietitian.

Access to specific services – Dental services

NICE CSG6 – Recommendation 2

The MDT should be responsible for ensuring that specialised dentistry is available for all patients who require it. Expert dental assessment and treatment is important both before and after treatment, especially when radiotherapy is being considered. Many of these patients have complex needs that cannot be adequately met by primary care dental services. A consultant with experience in maxillofacial prosthetics and implantology is required to manage patients who need oral rehabilitation. This consultant should co-ordinate the dental care of patients after treatment by liaison with primary care dental practitioners.

Systemic staging

Clinical staging – who and how?

NICE NG36 – Recommendations 1.2.9 and 1.2.10

1.2.9 Offer FDG PET-CT to people with T4 cancer of the hypopharynx or nasopharynx.

1.2.10 Offer FDG PET-CT to people with N3 cancer of the upper aerodigestive tract.

FDG PET-CT to detect primary site

Identifying the occult primary

NICE NG36 – Recommendation 1.2.3

Consider a fluorodeoxyglucose positron emission tomography (FDG PET)-CT scan as the first investigation to detect the primary site in people with metastatic nodal squamous cell carcinoma of unknown origin that is thought to arise from the upper aerodigestive tract.

4.1.3 Current UK practice

MDT

The 2015 head and neck cancer peer review[5] reported that 71% of upper aero digestive tract and thyroid cancer MDTs had a restorative dentist core team member (35/49 teams).

It also noted that there were many examples of good practice at network level, including further increasing dietetic support.

[5] National Peer Review Report: Head and neck cancer services 2013/14, National Peer Review Programme

The national head and neck cancer audit 2014[6] did not specifically comment on the composition of the MDT. It reported that of the people diagnosed with head and neck cancer:

- 35.4% had a pre-treatment dental assessment
- 31.7% had a pre-treatment nutritional assessment
- 27.4% had a speech and language therapy pre-treatment assessment.

Systemic staging / FDG PET- CT to detect primary site

The national head and neck cancer audit 2014 reported that of 7,252 patients diagnosed in England and Wales between 1 November 2013 – 31 October 2014, 5,963 (82.2%) had undergone pre-treatment imaging of the primary site. This was done using PET (positron emission tomography) CT, CT (computerized tomography), MRI (magnetic resonance imaging) or ultrasound.

10.6% of patients in England were recorded as having undergone PET CT prior to treatment. The most frequent anatomic sites where PET CT was carried out were for pharyngeal disease, with 23% for nasopharynx cases, 19.3% for oropharynx and 15.5% for hypopharynx. Wide variation of between 2.9% - 21.9% of newly diagnosed patients undergoing PET CT was reported across England and Wales.

FDG PET-CT for detection of residual disease

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.1.4 Resource Impact

In the resource impact work for NG36, it was considered that the additional costs of using PET-CT for systemic staging, would be offset by savings from avoided treatments costs by ensuring people are on the appropriate pathway.

The other areas were not included in the resource impact assessment for NG36. They were not identified as areas that would have a significant resource impact (>£1m in England each year).

[6] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC

4.2 Treatment of early disease

4.2.1 Summary of suggestions

Sentinel lymph node biopsy

Stakeholders highlighted that sentinel lymph node biopsy (SLNB) should be offered to people with early oral cavity cancer (T1/T2 N0) who are not otherwise planned to have neck access procedures. Staging oral cancer with SLNB for these patients is a minimally invasive surgical procedure that takes less theatre time and results in patients having quicker recovery. It can also lead to patients being discharged home much earlier compared to elective neck dissection (END) which is invasive surgery with significant morbidity and risks.

Stakeholders commented that current practice in most centres is to offer neck dissection but sentinel lymph node biopsy exists as an alternative. This has the potential advantage of minimising surgical morbidity but would require specific training and expertise.

Patient choice of surgery or radiotherapy

A stakeholder commented that patients should be provided with a choice of treatment of surgery or radiotherapy where similar outcomes are seen e.g. early stage laryngeal and oropharyngeal cancers. In the treatment of early stage laryngeal cancer and oropharyngeal cancer, evidence from DAHNO reports suggest the types of treatment patients have received are very different to what would be expected from patient choice and vary between networks and even MDTs.

Access to comprehensive surgical reconstruction

A stakeholder commented that access to a full range of surgical reconstruction techniques remains highly variable. Peer review has highlighted that in some areas very little free flap reconstruction is offered to patients even though it is regarded as a standard of care. In the majority of units offering reconstruction the number of techniques or flaps offered is relatively small. In some units no bony reconstruction is offered.

Trans-oral robotic surgery (TORS)

Stakeholders commented that robotic surgery in head and neck cancer is an emerging technique, which needs to be rationalised in terms of delivery and based around a regional or supra-regional service. The indications are currently expanding but are likely to be refined over time to a much more limited portfolio.

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Sentinel lymph node biopsy	**Management of the N0 neck in T1–2 squamous cell carcinoma of the oral cavity** NICE NG36 Recommendation 1.3.5
Patient choice of surgery or radiotherapy	**Squamous cell carcinoma of the larynx/ Management of the N0 neck in T1–2 squamous cell carcinoma of the oral cavity** NICE NG36 Recommendations 1.3.2, 1.3.3 and 1.3.6
Access to comprehensive surgical reconstruction	Not directly covered in NICE NG36 and no recommendations are presented
Trans-oral robotic surgery (TORS)	Not directly covered in NICE NG36 and no recommendations are presented

Sentinel lymph node biopsy

Management of the N0 neck in T1–2 squamous cell carcinoma of the oral cavity

NICE NG36 Recommendation 1.3.5

Offer sentinel lymph node biopsy instead of elective neck dissection to people with early oral cavity cancer (T1–T2, N0), unless they need cervical access at the same time (for example, free-flap reconstruction).

Patient choice of surgery or radiotherapy

Squamous cell carcinoma of the larynx/ Management of the N0 neck in T1–2 squamous cell carcinoma of the oral cavity

NICE NG36 Recommendations 1.3.2, 1.3.3 and 1.3.6

Squamous cell carcinoma of the larynx
1.3.2 Offer a choice of transoral laser microsurgery or radiotherapy to people with newly-diagnosed T1b–T2 squamous cell carcinoma of the glottic larynx.

1.3.3 Offer a choice of transoral surgery or radiotherapy to people with newly-diagnosed T1–T2 squamous cell carcinoma of the supraglottic larynx.

Squamous cell carcinoma of the oropharynx (T1–2, N0)

1.3.6 Offer people the choice of transoral surgical resection or primary radiotherapy for T1–2 N0 tumours of the oropharynx.

4.2.3 Current UK practice

Sentinel lymph node biopsy

In March 2016 the Head and Neck Cancer Foundation[7] reported that sentinel node biopsy for treating mouth cancer is available in one centre in the UK.

Patient choice of surgery or radiotherapy

The national head and neck cancer audit 2014[8] asked whether people are being provided with choice of radiotherapy or transoral endoscopic surgery for suitable cancers. It identified early larynx cancer (T1 N0 and T2 N0 squamous carcinoma) as suitable and found that, of the 844 cases submitted, 52.1% received radiotherapy as first treatment and 45% received surgery which was consistent with the previous year's figures. It noted that there appears to be established practice with cancer networks and strategic clinical networks showing similar patterns of treatment from year to year. No figures were provided regarding whether people were offered a choice.

The audit also reported that of the 2,439 cases of oropharynx cancer, 1,937 had curative treatment intent, with the majority – 1,079 (55.7%) – having non-surgical treatment as the first recorded treatment. Within the non-surgical treatment group, chemo-radiotherapy (620) is more than twice as frequent as radiotherapy (278) as the first treatment.

Access to comprehensive surgical reconstruction

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Trans-oral robotic surgery (TORS)

The 2015 head and neck cancer peer review[9] noted that there were many examples of good practice in upper aerodigestive tract and thyroid teams, including the introduction of robotic surgery however no figures were provided.

[7] Head and Neck Cancer Foundation website
[8] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC
[9] National Peer Review Report: Head and neck cancer services 2013/14, National Peer Review Programme

4.2.4 Resource Impact

The resource impact assessment for NG36 identified that there may be small savings for providers from carrying out sentinel lymph node biopsies. By offering a sentinel lymph node biopsy first it is estimated there would be a 70% reduction in neck dissection. Neck dissection requires an average stay in hospital of 5 days. People having sentinel lymph node biopsy are anticipated to need a 1 day stay in hospital, because it is less invasive. As there could be around 250 people who will no longer need a neck dissection it is estimated providers would save around 1,000 bed days. There is no resource impact for commissioners from this recommendation as both sentinel lymph node biopsy and neck dissection are both coded to the same healthcare resource group (HRG).

The other areas were not included in the resource impact assessment for NG36. They were not identified as areas that would have a significant resource impact (>£1m in England each year).

4.3 Optimising rehabilitation and function

4.3.1 Summary of suggestions

Dental rehabilitation

A stakeholder commented that access to dental implants following major reconstruction of the jaw is far from uniform and many patients have to make do with poorly fitting obturators.

A stakeholder commented that appropriate discussion with a consultant in restorative dentistry at the time of treatment planning and as treatment progresses will allow a long term rehabilitation plan to be defined. Patient quality of life can be substantially improved in terms of function (speech, mastication) and aesthetics, by appropriate oral rehabilitation.

Enteral nutrition support

A stakeholder commented that the importance of nutrition in people with cancer of the upper aerodigestive tract is well established due to the effects of the disease and its treatment on the ability to eat and drink. Malnutrition affects treatment outcomes, quality of life and healthcare costs.

Best supportive care

A stakeholder commented that teams should plan proactive management of an airway which may be at risk. Early identification is often lacking and endoluminal debulking is often not attempted due to a lack of local expertise resulting in default tracheostomy which in turn can delay discharge. In addition there is often little community support for patients with tracheostomies.

A stakeholder commented that symptom management should be provided for patients referred for best supportive care. There is little evidence as to how to best support head and neck squamous cell carcinoma patients who often have distressing symptoms.

Timely rehabilitation

A stakeholder commented that people with head and neck cancer should receive timely post-treatment rehabilitation and survivorship interventions as these are crucial to patient quality of life and return to work.

A stakeholder commented that early physiotherapy for shoulder impairment following neck dissection should be considered. There is evidence to show the use of progressive resistance training improves function however physiotherapy is often not

instigated in a proactive way and shoulder examination is often not part of routine post-operative practice.

Community rehabilitation

A stakeholder commented that people undergoing radical treatment (surgical and non-surgical) for upper aerodigestive tract cancer have significant morbidity and specialist rehabilitation in the community can significantly improve quality of life without placing additional burden on hospital services.

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Dental rehabilitation	**Dental assessment** NICE CSG6 Recommendation 4 **Local support team members** NICE CSG6 Recommendation 6
Enteral nutrition support	**Enteral nutrition support** NICE NG36 Recommendations 1.7.1 and 1.7.2
Best supportive care	**Palliation of breathing difficulties** NICE NG36 Recommendations 1.4.8 and 1.4.9
Timely rehabilitation	**Shoulder rehabilitation** NICE NG36 Recommendation 1.7.6
Community rehabilitation	**Optimising rehabilitation and function** NICE NG36 Recommendations 1.7.1, 1.7.2, 1.7.3, 1.7.4, 1.7.5 and 1.7.6

Dental rehabilitation

Dental assessment

NICE CSG6 – Recommendation 4

Patients' dental prostheses should be assessed, along with the denture-bearing ridges, to check that the prosthesis is both comfortable and effective.

Local support team members

NICE CSG6 – Recommendation 6

Oral rehabilitation should be provided by the specialist restorative dentist for all patients who require it. This dentist should co-ordinate continuing dental care for these patients and take responsibility for long-term liaison with other dentists who may treat them.

Enteral nutrition support

NICE NG36 Recommendations 1.7.1 and 1.7.2

1.7.1 Assess people's need for enteral nutrition at diagnosis, including prophylactic tube placement. The multidisciplinary team should take into account:

- performance status and social factors
- nutritional status (weight loss, high or low BMI, ability to meet estimated nutritional needs)
- tumour stage
- tumour site
- pre-existing dysphagia
- impact of planned treatment (such as radiation treatment volume and dose-fractionation, concomitant chemotherapy, and extent and site of surgery).

1.7.2 Follow the recommendations in NICE's guideline on nutrition support for adults for people aged 18 years and over.

Best supportive care

Palliation of breathing difficulties

NICE NG36 Recommendations 1.4.8 and 1.4.9

1.4.8 Identify people at risk of airways obstruction for whom intervention is appropriate. Think about:

- their performance status
- treatment side effects and length of hospital stay
- involving the palliative care team and other specialists when appropriate.

1.4.9 Consider endoluminal debulking in preference to tracheostomy.

Timely rehabilitation / Community rehabilitation

Optimising rehabilitation and function

NICE NG36 Recommendations 1.7.3, 1.7.4, 1.7.5 and 1.7.6

Speech and language therapy interventions

1.7.3 Consider swallowing-exercise programmes for people having radiotherapy.

1.7.4 Consider mouth-opening exercises for people having radiotherapy who are at risk of reduced mouth opening.

1.7.5 Consider voice therapy for people whose voice has changed because of their treatment.

Shoulder rehabilitation

1.7.6 Consider progressive resistance training for people with impaired shoulder function, as soon as possible after neck dissection.

4.3.3 Current UK practice

Rehabilitation - general

The 2015 head and neck cancer peer review[10] reported that 96% of upper aerodigestive tract and thyroid cancer MDTs had aftercare and rehabilitation protocol.

Dental rehabilitation

The national head and neck cancer audit 2014[11] reported that 35.4% of people diagnosed that year had a pre-treatment dental assessment. It noted that all patients should receive a pre-treatment dental assessment but the audit currently does not record whether a patient has no teeth. It noted that patients may be being excluded from assessment if they have no teeth however they would benefit from screening to exclude pathology within the jaws that could cause problems, during or after treatment, such as osteoradionecrosis (bone death due to radiation). The audit noted that there are shortages of restorative dentists working with head and neck cancer patients.

Enteral nutrition support

[10] National Peer Review Report: Head and neck cancer services 2013/14, National Peer Review Programme
[11] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC

The national head and neck cancer audit 2014[12] reported that 52.5% of people diagnosed in England, whose treatment was recorded, had a nutrition record. Where there was a nutrition record, 73% confirmed the predominant method of nutritional support during treatment. Of these patients, 47.3% received enteral tube feeding, with 35% managing oral nutrition support alone, 14.4% requiring no nutritional support and 0.7% requiring parenteral nutrition.

Best supportive care

The national head and neck cancer audit 2014 reported that, of the people diagnosed in England and Wales where their first treatment was recorded, approximately 4% received palliative care as first treatment.

No published studies on current practice were highlighted for management of an airway which may be at risk; this area is based on stakeholder's knowledge and experience.

Timely rehabilitation / community rehabilitation

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.3.4 Resource impact

This area was considered not to have a significant resource impact (>£1m in England each year) in the resource impact assessment for NG36. It was noted that speech and language services may need to reorganise, but this should be possible within current resources.

[12] National Head and Neck Cancer Audit 2014, DAHNO Tenth Annual Report, HSCIC

4.4 Information and support

4.4.1 Summary of suggestions

Information

A stakeholder commented that provision of better information to patients with diagnosis of head and neck cancer is needed throughout their pathway. Head and neck cancer is a complex set of diseases with varied treatment and follow up pathways and every patient will benefit from improved information tailored to their needs and delivered at critical points along their treatment pathway. A stakeholder also commented that pre-treatment information on the potential effects of treatment should be given.

Named clinical nurse specialist (CNS)

A stakeholder commented that a named CNS or other designated key worker and their contact details should be provided for every patient. They suggested patients value having a key worker such as a CNS, as it makes care more patient-centred, and it has been shown to improve efficiency for example by reducing the number of consultations with a doctor.

4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Information	**Information needs** NICE NG36 Recommendations 1.1.1, 1.1.3 and 1.8.1
Named clinical nurse specialist (CNS)	**Information needs** NICE NG36 Recommendation 1.1.2

Information
Information needs

NICE NG36 Recommendations 1.1.1, 1.1.3 and 1.8.1

1.1.1 For people with cancer of the upper aerodigestive tract and their carers:

- provide consistent information and support at diagnosis

- review their needs throughout the care pathway including at the end of treatment

- tailor information and support to the person's needs (including the benefits and side effects of treatment, psychosocial and long-term functional issues).

1.1.3 Give people details of peer support services that can help them throughout their care pathway.

1.8.1 Ensure people with cancer of the upper aerodigestive tract and their carers have tailored information about the symptoms of recurrence and late effects of treatment at the end of curative therapy.

Named clinical nurse specialist (CNS)
Information needs

NICE NG36 Recommendation 1.1.2

1.1.2 Give people contact details for their allocated key worker, in line with the NICE service guidance on improving outcomes in head and neck cancer and recommendations of the National Peer Review Programme.

4.4.3 Current UK practice

Information

The national cancer patient experience survey 2015[13] included all adult (aged 16 and over) NHS patients with a confirmed primary diagnosis of cancer discharged from an NHS Trust after an inpatient or day case attendance for cancer related treatment in April – June 2015.

Respondents to the survey reported that:

- 72% were given written information about the type of cancer they had at diagnosis, and it was easy to understand.

- 54% were told about any side effects of the treatment that could affect them in the future rather than straight away before they started treatment.

- 83% of respondents with more than one treatment option had their options clearly explained before their treatment started.

- 73% had the possible side effects of treatment(s) explained to them in a way they could understand.

[13] National Cancer Patient Experience Survey 2015, Quality Health

- 81% received information about the impact cancer could have on their day to day activities.

The 2015 head and neck cancer peer review[14] noted that 98% of upper aerodigestive tract and thyroid MDTs met the peer review measure of the provision of written patient information for upper aerodigestive tract cancer.

Named clinical nurse specialist (CNS)

The 2015 head and neck cancer peer review reported that 62.9% of people with head and neck cancer were seen by a CNS before starting treatment. This was a reduction of 1.8% from the previous year. There was wide variation in practice with networks reporting figures of between 29.7% and 85.1%.

The national cancer experience survey 2015[15] reported that 90% of respondents said they were given the name of a CNS who would support them through their treatment.

4.4.4 Resource impact

This area was not included in the resource impact assessment for NG36. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

[14] National Peer Review Report: Head and neck cancer services 2013/14, National Peer Review Programme
[15] National Cancer Patient Experience Survey 2015, Quality Health

4.5 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 14 July 2016.

HIV

A stakeholder commented that there are very few HIV+ patients with head and neck cancers. They stated that people with head and neck cancer requiring chemotherapy or radiotherapy should be tested for HIV as per HIV malignancy guidelines (and treated if HIV+). People with head and neck cancer and HIV should not be excluded from clinical trials because of their HIV status alone.

The source guideline does not contain recommendations on this area.

2 week suspected cancer referral / Detection and diagnosis

Stakeholders commented that recent and revised NICE guidance has excluded some areas which should be included as part of the 2 week wait criteria and are poor in identifying people with a significant risk of head and neck cancer.

A stakeholder commented that more than half of head and neck cancers are diagnosed at an advanced stage and there appears to have been little improvement in survival rates over recent decades. More effort is needed on early detection of head and neck cancers, given the poor outcomes associated with advanced disease.

A stakeholder commented that there is a need for earlier referral to specialist services for diagnosis and treatment planning, and a reduction in the number of patients referred with advanced stage head and neck squamous cell carcinoma.

NICE quality standard 124 suspected cancer contains statements on suspected cancer referrals.

Quality standards are based on existing NICE or NICE accredited guidance. Updating recommendations within guidelines is not part of the quality standards process however this information will be provided to the guidelines team.

Shared decision making and information

A stakeholder commented that because patients are central to decision making in their care it is important that they are offered the most current treatment options. The surgical and oncological treatment options should be presented or the patient should be offered best supportive care where appropriate.

A stakeholder commented that information on local care services should be available and any choice of service should be given to all patients at time of diagnosis. Head and neck cancers can have devastating effects on the lives of patients and carers; the treatment can have a profound impact on the way the patient looks, talks, eats, or breathes, which can severely impact their overall quality of life. Patients with head and neck cancer are at particular risk of psychological problems, particularly social anxiety and depression.

NICE quality standard 15 patient experience in adult NHS services addresses these areas.

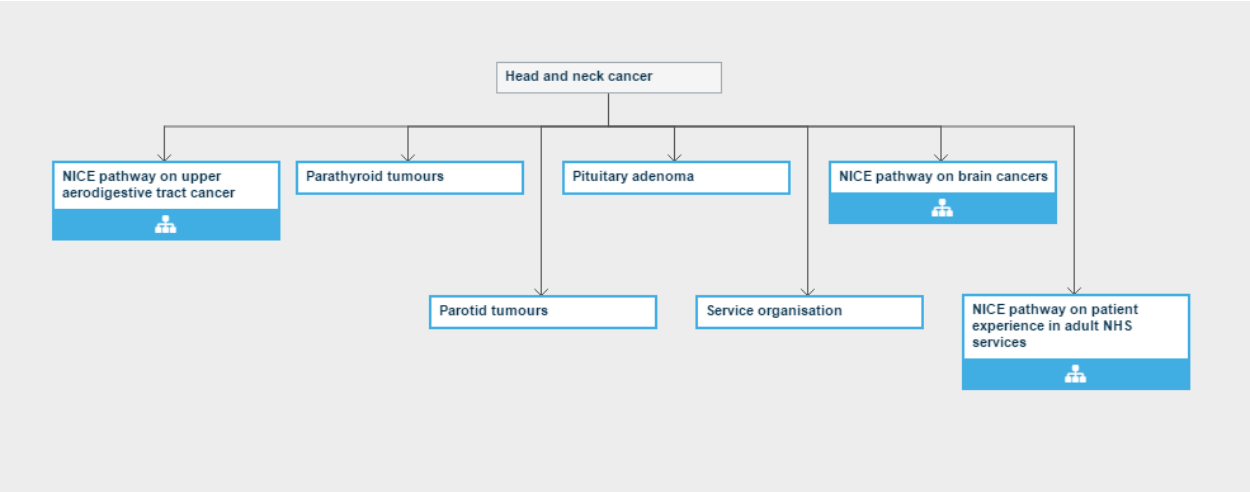
Public awareness

A stakeholder commented that public awareness of head and neck cancers is low, probably because of its relative rarity. There is a clear need to inform and educate the public in matters relating to the known risk factors associated with head and neck cancers and potential signs or symptoms suggestive of head and neck cancers.

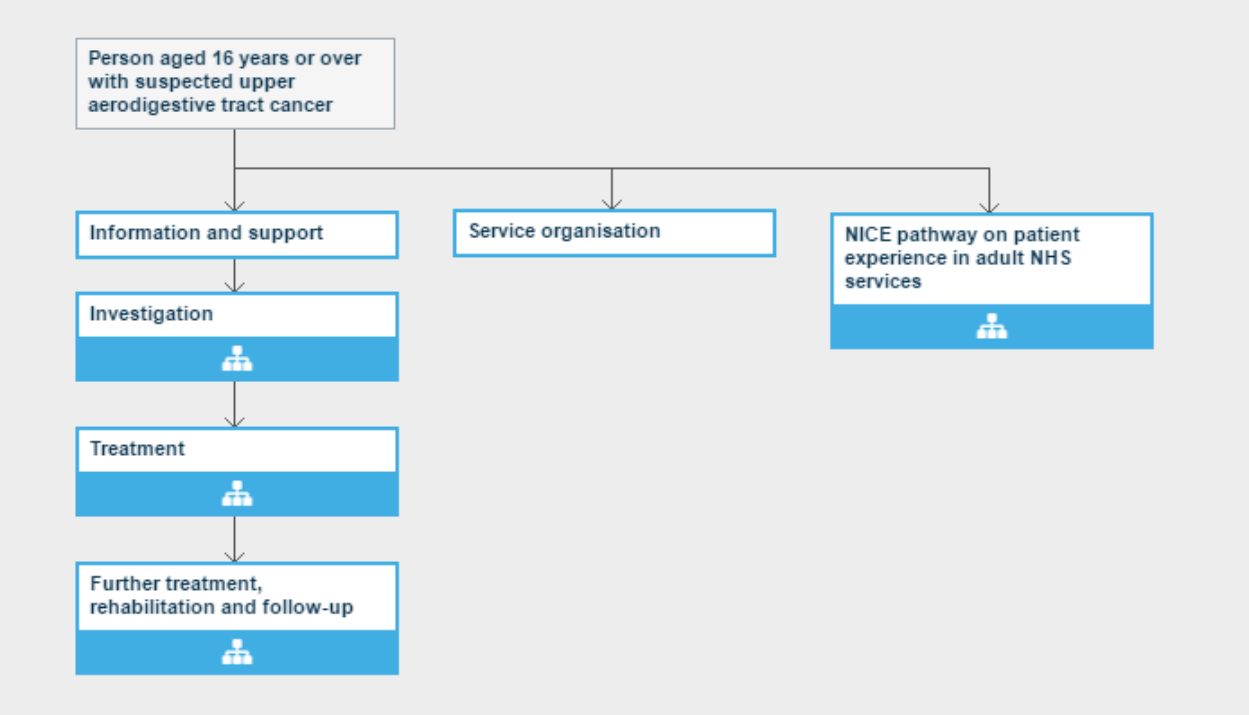
Public awareness campaigns and strategies are not within the remit of quality standards.

Appendix 1: Additional information

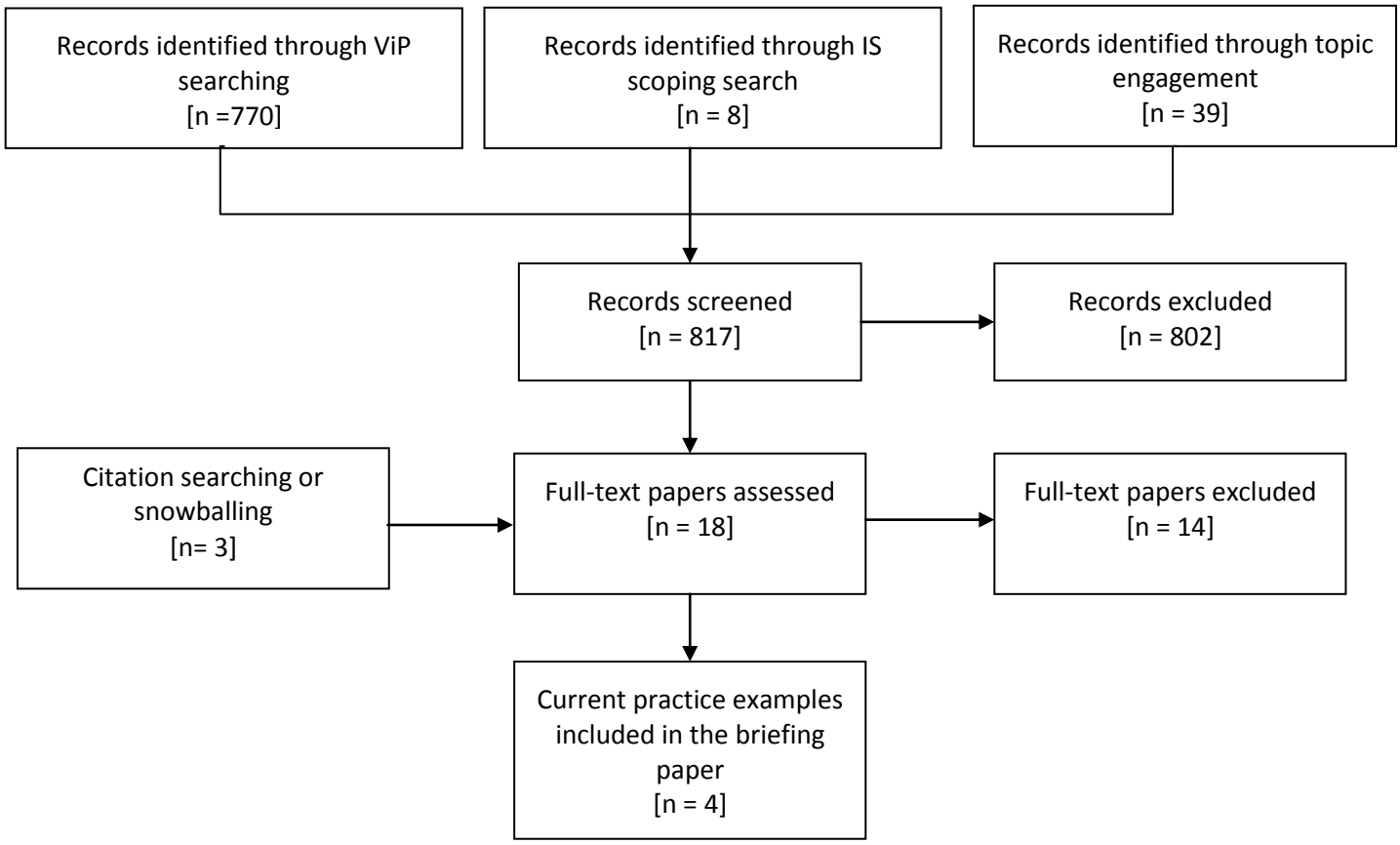
Head and neck cancer overview



Upper aerodigestive tract cancer overview



Appendix 2: Review flowchart



Appendix 3: Glossary

Sentinel lymph node biopsy (SLNB)

Surgical removal of the first lymph node or group of nodes (the sentinel node) draining a cancer.

[Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guideline NG36, full guideline glossary (appendix E)]

Stage

The stage of cancer describes how big it is and whether it has spread. For the stages of cancer used in this quality standard there will be a T number and an N number (for example, T1N0). The T and N stand for:

T0: this means there is no primary tumour, but there may be abnormal cells that are precancerous.

T1 to T4: this refers to the increasing size and/or extent of the primary tumour, with 1 being smallest and 4 largest.

N0: no lymph nodes contain cancer cells.

N1 and upwards: increasing involvement of lymph nodes by cancer cells.

[Adapted from cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guideline NG36, information for the public]

Staging

Clinical description of the size and spread of a patient's tumour, fitting into internationally agreed categories.

[Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guideline NG36, full guideline glossary (appendix E)]

Systemic staging

Investigations carried out to determine if a cancer has spread beyond the primary site.

[Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guideline NG36, full guideline glossary (appendix E)]

Appendix 4: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Investigation			
1	ENT UK	Restorative dentistry	Restorative dentistry is very poorly represented in MDTs across the country as evidenced by DAHNO and other surveys of MDT participation. Every MDT is supposed to have a named restorative dentist. More than 75% of H&N cancer patients will receive radiotherapy and without a formal assessment and removal of at risk teeth may suffer osseoradionecrosis following treatment. Patients who have had extensive mandibular or maxillary resection need planned dental rehabilitation.	Peer review has consistently shown variability in the availability and quality of dental rehabilitation across the UK	DAHNO, Peer review, BAHNO standards
2	RD-UK (Association of Consultants and Specialists in Restorative Dentistry)	100 % of MDTs should have one or more Consultants in Restorative Dentistry as core team members	Head and neck cancer treatment can have devastating and debilitating long-term oral and dental side effects; the main ones being problems with function and appearance, very limited mouth opening, dry mouth, widespread destructive dental decay and periodontal disease and osteoradionecrosis. These can be extremely distressing for patients, long after discharge from cancer follow up. They can be highly challenging and costly to treat, and have significant consequences on patient quality of life. Minimising and even avoiding these problems can be achieved by having clinical staff (consultant and supporting team, including a	Over the last 10 years, DAHNO and the Peer review process have noted this to be a neglected area but have noted it is an area which has greatly improved over that period. With around 70% of MDTs now being shown to have one or more Restorative Consultants in the team, this has been an area of significant improvement but it is now essential to ensure that 100% of teams reach this target. In the past this problem has been neglected and even trivialised; the assumption being made that any,dentist, without appropriate specialist training, could fulfil this role. It is essential that patients should have access to the appropriate level of expertise, skill and training to help them achieve the best possible outcomes.	Improving outcomes in Head and Neck Cancer clearly states that Restorative Dentistry should have input throughout the patient journey. DAHNO and Peer Review have noted an improvement but have highlighted certain teams still failing to reach the standard.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			dedicated hygienist) available with the correct level of training and expertise involved from the point of diagnosis and throughout the patient journey. The Restorative specialist is the only dentist who has this comprehensive set of skills and the specific training to be able to carry out complex oral rehabilitation. Having this input throughout the patient's cancer treatment ensures the best possible outcomes and helps maximise the chance of early discharge to primary care for long term follow up.		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
3	SCM3	Optimisation of systemic staging in patients diagnosed with head and neck cancer	Distant metastases are less common in head and neck cancer than in many other cancers but their presence at diagnosis usually precludes curative treatment. Accurate systemic staging can identify patients best served by a palliative approach, often sparing them the significant morbidity of surgery or high dose radiotherapy. Staging can also detect synchronous primary cancers. Patients with different tumour sites and stages have different risks of systemic disease. There is also debate about which imaging tests usually used for systemic staging are most accurate. There are potential harms associated with these imaging tests including radiation exposure and the discovery of incidental problems which may complicate care. There are also potential financial costs. This has resulted in variation in current practice across the UK.	The recent NICE guidance concluded that using conventional imaging as the systemic staging strategy was cost-effective in the majority of patient populations. Notable exceptions were the T1N0 and T2NO patient subgroups, in whom no imaging was found to be the optimal strategy because of the low number of patients with systemic disease. FDG PET-CT was found to be more cost-effective than conventional imaging in high risk groups (i.e. groups with high prevalence of distant metastases). This was most evident in patients with N3 disease at any subsite, T4 nasopharynx or T4 hypopharynx cancer, where FDG PET-CT was found to be dominant. The potential benefits of the NICE recommendations are: More targeted use of systemic imaging Avoiding unnecessary investigations/radiation exposure in patients who are at very low risk of systemic disease. Avoiding over-investigation of incidental and insignificant abnormalities identified by imaging of patients at very low risk of systemic disease. The potential harms of the NICE recommendations are: Patient anxiety from not being tested In the patient groups who should not routinely receive systemic imaging, a very small proportion will have systemic disease that goes initially undetected. Some patients will therefore require later systemic imaging, after surgery for example. Not detecting systemic disease in a small proportion	Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guidelines [NG36] Published date: February 2016 Resource impact report: Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over(NG36)

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				of low-risk patients is outweighed by the large number of unnecessary investigations avoided, and the false positive tests avoided.	
4	SCM1	Key area for **quality improvement 2**: Offer FDG PET-CT to people with T4 cancer of the hypopharynx or nasopharynx.	It will lead to more accurate systemic staging, more appropriate treatment and spare some patients treatments they are unlikely to benefit from	There is currently variation in practice in this area	Current NICE upper aerodigestive tract cancer guidelines [NG 36]
5	SCM1	Key area for **quality improvement 3**: Offer FDG PET-CT to people with N3 cancer of the upper aerodigestive tract.	It will lead to more accurate systemic staging, more appropriate treatment and spare some patients treatments they are unlikely to benefit from	There is currently variation in practice in this area	Current NICE upper aerodigestive tract cancer guidelines [NG 36]
6	SCM2	People presenting with extensive nodal disease (N3) should be offered systemic staging with FDG PET-CT	Identification of distant disease will prevent a cohort of patients undergoing treatment with potential morbidity who are incurable	Identification of patients who should be treated with palliative intent allows early symptom-directed care and minimises morbidity	Cancer of the upper aerodigestive treact: assessment and management in people aged 16 and over. NICE NG36
7	SCM1	Key area for **quality improvement 1**: Consider FDG PET CT as the first investigation to detect the primary site in people with metastatic nodal squamous cell carcinoma of unknown origin that is thought to arise from the upper aerodigestive tract.	It will improve patient experience by reducing number of visits to hospital for investigations prior to a diagnosis	Currently there is variation in the diagnostic pathway for people with metastatic nodal squamous cell carcinoma of unknown origin that is thought to arise from the upper aerodigestive tract and the majority of patients have other investigations including CT / MR / both before FDG PET CT	Current NICE upper aerodigestive tract cancer guidelines [NG 36]

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
8	SCM2	People presenting with cervical lymphadenopathy who are diagnosed with metastatic squamous cell carcinoma of unknown primary are offered FDG PET-CT as first line radiological investigation	Although relatively uncommon accurate identification of primary site often obviates need for more extensive treatment (eg: TMI)	Diverse existing protocols Patients often offered multiple imaging modalities with ensuing costs	Cancer of the upper aerodigestive treact: assessment and management in people aged 16 and over. NICE NG36
9	SCM3	Identification of the Occult primary using FDG-PET as the primary investigation.	A small proportion of patients with head and neck cancer present with a neck lump and no clinical evidence of cancer in the upper aerodigestive tract mucosa. Identification of the primary tumour is important to guide treatment planning and follow-up. When a primary tumour is not evident current practice involves biopsy of several mucosal sites. While there is broad consensus to perform radiological investigations prior to biopsy there is no agreement on the precise tests to be used. This may result in a delay in the diagnostic process. The potential benefits of offering a fluorodeoxyglucose positron emission tomography (FDG PET)- CT scan as the first investigation to detect the primary site in people with metastatic nodal squamous cell carcinoma of unknown origin that is thought to arise from the upper aerodigestive tract are:	The main changes in practice as a result of implementing the NICE recommendations to be: • Greater use of FDG PET-CT • Less use of other cross-sectional imaging investigations • Greater use of narrow band imaging. Currently FDG-PET may be used to evaluate these patients in some centres but not as first investigation and thus patients may be subject to unnecessary extra investigations.	Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guidelines [NG36] Published date: February 2016

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			• Earlier detection of primary tumours, with minimal burden of testing for the patient • Detection of a higher proportion of primary tumours • Potentially reduced treatment related morbidity as a result of more targeted treatment.		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
10	SCM1	Additional developmental areas of emergent practice: FDG PET CT for detection of residual disease in people with advanced upper aerodigestive tract cancer treated with chemoradiotherapy	It will lead to a reduction in number of people with this condition having unnecessary surgery to the neck [neck dissection]	There is currently variation in practice in this area. It will result in better care for people with this condition and also result in some financial savings to the NHS	Please see "PET CT surveillance vs neck dissection in advanced head and neck cancer. New England J Medicine March 2016" which highlights the value of FDG PET CT scanning for people with this condition
		Treatment of early disease			
11	SCM2	Offer sentinel node biopsy (SNB) to people with early oral cavity cancer (T1/T2 N0) who are otherwise not planned for neck access procedures	Evidence to suggest proactive management of the neck confers survival benefit At present selective neck dissection often offered despite high sensitivity / specificity of SNB	SNB not at present routinely carried out	Cancer of the upper aerodigestive treact: assessment and management in people aged 16 and over. NICE NG36
12	SCM4	Sentinel lymph node biopsy in early oral cavity cancer	This was recommended in the CUADT guideline recently published. This represents a significant change in everyday clinical practice with surgeons having to learn new techniques & hospitals having to invest in new equipment.	Potentially 70% of patients will be spared unnecessary neck dissection surgery.	NICE guideline 36
13	NHS England	Key area for quality improvement 1 Sentinel lymph node biopsy for squamous cell carcinoma of the oral cavity	Potential for reducing treatment related morbidity – recommended in NICE NG36 Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over	Currently, sentinel lymph node biopsy for oral cavity cancer is not routinely available at the cancer centre in Thames Valley, although Oxford University Hospitals Trust is at the early stages of establishing a service.	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
14	Norgine	Key area for quality improvement 1 **Staging oral cancer with sentinel lymph node biopsy (SLNB) for those patients who are clinically node negative.**	There is growing body of evidence that patient who are clinically node negative after standard examination (physical examination, chest X Ray, CT head/neck/chest and often ultra sound) should be offered SLNB to stage the nodal involvement of the primary cancer. SLNB has demonstrated good diagnostic accuracy.	Both single centre and multicentre trials have demonstrated false negative rate (FNR) for SLNB that is approaching equivalent figures seen in SLNB in other cancers such as breast cancer where this diagnostic approach is the standard of care. SLNB has been recommended for T1-2 N0 oral cancer patient in European guidelines from European Association of Nuclear Medicine since 2009. Long term follow up studies have evaluated oncological safety of SLNB for patient at stage N0	Schilling c. et al Sentinel European Node Trial (SENT): 3-year results of sentinel node biopsy in oral cancer. European Journal of Cancer (2015) 1-8 Alkureishi L. et al. Joint practice guidelines for radionucleide lymphoscintigraphy for sentinel node localization in oral/oropharyngeal squamous cell carcinoma. Eur J Nucl Med Mol Imagine (2009) 36:1915-1936 Monroe M, Lai S Sentinel Lymph Node Biopsy for Oral Cancer: Supporting Evidence and Recent novel Developments. Curr Oncol Rep (2014) 16:385 Alkureishi LW. et al Sentinel node biopsy in head and neck squamous cell cancer: 5-year follow-up of a European multicentre trial. Ann Surg Oncol 2010 Sep;17(9):2459-64 Sentinel Lymph Node Biopsy Accurately Stages the

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					Regional Lymph Nodes for T1-T2 Oral Squamous Cell Cercinomas: Results of a Prospective Multi-Institutional Trial. Journal of Clinical Oncology 2010. Agrawal A et al. 99mTC Tilmanocept Accurately Detects Sentinel Lymph Nodes and Predicts Node Pathology Status in Patients with Oral Squamous Cell Carcinoma of the Head and Neck: Results of a Phase III Multi-institutional Trial. Ann Surg Oncol 2015;22(11):3708-3715

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
15	Norgine	Key area for quality improvement 2 **SLNB is a cost effective alternative to elective neck dissection (END) for staging oral cancer**	SLNB is minimally invasive surgical procedure that takes less theatre time, where patients have quicker recovery and discharged home much earlier compared to END.	Based on a cohort of 481 patients of European patients, a model simulation of the two pathways a) traditional surgical techniques and b) SLNB have demonstrated SLNB to be cost effective relative to the traditional surgical approach. A separate model from the Netherlands came to the same conclusion.	Gover TM et al. Cost-effectiveness for selective neck dissection versus modified radical neck dissection for treating metastases in patients with oral cavity cancer: A modelling study. Head&Neck (2015) O'Connor R et al The relative cost of sentinel lymph node biopsy in early oral cancer. Journal of Cranio-Maxillo-Facial surgery 41 (2013) 721-727 Gover TM et al Management of the N0 neck in early stage oral squamous cell cancer: A modelling study of the cost-effectiveness. Oral Oncology 49(2013) 771-777
16	Norgine	Key area for quality improvement 3 Patients undergoing END incur significant impairment of their quality of life and morbidity	Currently most centres do not offer SLNB and use END to stage oral cancer. Up to 80% of patients (T1-T2 N0) who undergo END are true node negative and have had the surgery unnecessarily. END is invasive surgery with significant morbidity and risks involved.	Surgical risks with END are bleeding, fistulas, accessory nerve damage with shoulder and arm dysfunction, facial nerve damage (mandibular branch), vagal,hypoglossal and phrenic nerves can be damaged and direct damage to the carotid wall. The incidence of these complications have been reported by Harreus. These can lead to chronic impact on quality or life of patients with impairment of speech, swallowing, shoulder movement and cosmetical defect.	Schilling c. et al Sentinel European Node Trial (SENT): 3-year results of sentinel node biopsy in oral cancer. European Journal of Cancer (2015) 1-8 Alkureishi L. et al. Joint practice guidelines for radionucleide lymphoscintigraphy for sentinel node localization in oral/oropharyngeal

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					squamous cell carcinoma. Eur J Nucl Med Mol Imagine (2009) 36:1915-1936 O'Connor R et al The relative cost of sentinel lymph node biopsy in early oral cancer. Journal of Cranio-Maxillo-Facial surgery 41 (2013) 721-727 Pedersen A et al Swallowing outcome measures in head and neck cancer- How do they compare? Oral Oncol 2016 Jan;52: 104-8 Gover TM et al Quality of life after different procedures for regional control in oral cancer patients: cross-sectional survey. Clin Otolaryngol 2016 Jun; 41(3):228-33 Harreus U Surgical errors and risks – the head and neck cancer patients. GMS Curr Top Otorhinolgryngol Head Neck Surg v12 2013

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
17	Norgine	Key area for quality improvement 4 Effective development of service delivery	The recommended procedure of SLNB has been widely reported to be technically complex, operator-sensitive and involves a learning curve for surgeons. Surgeons who conduct SLNB for head and neck cancer patients will need to undergo rigorous training to ensure an effective change from the current practice of elective neck dissection to SLNB.	The quality of this training will need to be maximised through appropriate standardisation as well as the use of optimal techniques. The provision of key service delivery components will also need to be ensured to include pathology services and appropriate camera imaging time with the nuclear medicine service.	Schilling c. et al Sentinel European Node Trial (SENT): 3-year results of sentinel node biopsy in oral cancer. European Journal of Cancer (2015) 1-8
18	Norgine	Key area for quality improvement 5 The utilisation of optimal tools for successful outcomes (choice of Radiotracer used to identify the sentinel node)	In addition of training of surgeons and service set up; using the best available technology, equipment and radioactive tracers will help to improve quality and outcome of patients.	The technical complexity of SLNB in head and neck cancer patients means that optimisation is highly necessary to ensure desired outcomes. The choice of radiotracer used to identify the sentinel lymph node plays a key role in ensuring these desired outcomes. An effective radiotracer needs to be specifically designed to identify sentinel lymph nodes and demonstrate a low false negative rate particularly in patients with Floor of Mouth (FOM) tumours who have been shown to have the highest failure rate in SLNB.	Schilling c. et al Sentinel European Node Trial (SENT): 3-year results of sentinel node biopsy in oral cancer. European Journal of Cancer (2015) 1-8 Agrawal A et al. 99mTC Tilmanocept Accuratlely Detects Sentinel Lymph Nodes and Predicts Node Pathology Status in Patients with Oral Squamous Cell Carcinoma of the Head and Neck: Results of a Phase III Multi-institutional Trial. Ann Surg Oncol 2015;22(11):3708-3715

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
19	SCM3	Management of the N0 neck in T1–2 squamous cell carcinoma of the oral cavity	The management of the neck in early carcinoma of the oral cavity remains controversial. Elective neck dissection is commonly performed but reveals occult metastases in around 25%. Therefore the majority of neck dissections in this group are unnecessary. However identification and treatment of those with occult metastases confers a survival benefit. Current practice in most centres is to offer a selective neck dissection but sentinel lymph node biopsy exists as an alternative. This has the potential advantage of minimising surgical morbidity but would require specific training and expertise.	Currently, people with early oral cavity cancer may have a neck dissection to remove lymph nodes. By offering a sentinel lymph node biopsy first it is estimated there would be a 70% reduction in neck dissection. Both neck dissection and sentinel lymph node biopsy would be coded to the same healthcare resource group codes CZ17V and CZ17Y, with or without complications and comorbidities. Neck dissection requires an average stay in hospital of 5 days. People having sentinel lymph node biopsy are anticipated to need a 1 day stay in hospital, because it is less invasive. As there could be around 250 people who will no longer need a neck dissection it is estimated providers would save around 1,000 bed days. The 2015/16 ETO tariff price is £2,119 for CZ17V and £1,347 for CZ17Y. Follow up physiotherapy costs are also estimated to reduce.	Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guidelines [NG36] Published date: February 2016 Resource impact report: Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over (NG36)
20	SCM5	Provide patients with a choice of treatment of surgery or radiotherapy where similar outcomes are seen e.g. early stage laryngeal and oropharyngeal cancers.	Recent Nice guidance indicates patients should be provided with a choice of treatment in these situations. Presented with information about what the treatment will involve the potential side-effects (including late effects) they can then make a fully informed choice.	In the treatment of early stage laryngeal cancer and oropharyngeal cancer, evidence from DAHNO reports suggest treatment modalities undergone are very different to what would be expected from patient choice. There are great variations between networks and even MDTs and the patterns have persisted with little change for some years. Is patient choice being limited by the preference of clinicians, resourcing issues or other factors?	DAHNO Reports 9,10

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
21	ENT UK	Access to comprehensive surgical reconstruction	Access to a full range of surgical reconstruction techniques remains highly variable. Peer review has highlighted that in some areas very little free flap reconstruction is offered to patients even though it is regarded as a standard of care. In the majority of units offering reconstruction the number of techniques or flaps offered is relatively small. In some units no bony reconstruction is on offer.	Peer review has consistently shown variability in the availability and quality of reconstruction available to head an neck cancer patients. The better the reconstruction the easier it is for patients to return to normal daily tasks of living and the less the burden on the NHS from depression, voice restoration and supplemental feeding.	DAHNO, Peer review, BAHNO standards
22	ENT UK	Provision of specialist AHP for H&N	Many MDTs have limited access to non specialist dieticians and speech and language therapists. H&N patients have specific pre and post treatment dietary and swallowing issues as well as communication problems, which need the input of more focused and specialised AHPs.	Peer review has consistently shown variability in the availability and quality of specialist AHPs. Patients who are assessed and pre-treated by specialist AHPs have better outcomes and reduced hospital stay.	DAHNO, Peer review, BAHNO standards
23	SCM2	Additional developmental areas of emergent practice	TORS (Trans-Oral Robotic Surgery (TORS)		
24	ENT UK	Robotic surgery	Robotic surgery in the H&N is an emerging technique, which needs to be rationalised in terms of delivery and based around a regional or supraregional service. The indications are currently expanding but are likely to be refined over time to a much more limited portfolio.	The expense of the robot itself and surgical consumables means that there should be an NHS strategy employed to ensure equitable access to the technique for those patients most suited to it. At the moment the service is developing on the back of local enthusiasm.	Recent review commissioned by the H&N CRG
		Optimising rehabilitation and function			
25	ENT UK	Access to dental implants	As above, the access to dental implants following major reconstruction of the jaw is far from uniform and many patients have to make do with poorly fitting obturators	Peer review has consistently shown variability in the availability and quality of dental rehabilitation across the UK	DAHNO, Peer review, BAHNO standards
26	RD-UK	Optimising	Appropriate discussion with a Consultant in	Patient quality of life can be substantially improved	Improving outcomes in Head

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	(Association of Consultants and Specialists in Restorative Dentistry)	rehabilitation and function	Restorative Dentistry at the time of treatment planning and as treatment progresses will allow a long term rehabilitation plan to be defined	in terms of function (speech, mastication) and aesthetics, by appropriate oral rehabilitation	and Neck Cancers clearly states that Restorative Dentistry Specialists should have input throughout the patient journey. This is key to quality improvement in long term rehabilitation.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
27	SCM3	Enteral nutrition support	The importance of nutrition in the CUADT population is well established due to the effects of the disease and its treatment on a patient's ability to eat and drink. Malnutrition affects treatment outcomes, quality of life, and healthcare costs. Existing NICE guidance (Nutrition support in adults) recommends that if enteral feeding is required for longer than four weeks a gastrostomy tube should be used in preference to a nasogastric tube. The optimal method of tube feeding remains unclear and complications can occur.	The clinical benefits of the NICE recommendations would be reduced weight loss and malnutrition, with better quality of life as clinical outcomes. Patients may also be more likely to complete their course of treatment without interruption and some patients who do not require enteral nutrition may avoid feeding tube placement. Potential harms of the recommendation would be those associated with enteral feeding such as procedure-related morbidity/mortality, skin excoriation and the psychosocial impact. Screening and assessment of patients by a dietitian from the MDT (for suitability of the type of feeding tube and method of insertion) would help minimise these harms. Following assessment a decision would need to be made between prophylactic feeding versus oral nutritional support versus interventional tube feeding versus reactive tube feeding On balance the group believed that the reduction in malnutrition would outweigh any harms associated with enteral feeding.	Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over NICE guidelines [NG36] Published date: February 2016 Resource impact report: Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over (NG36)
28	SCM2	Plan proactive management of airway at risk	Early identification often lacking Endoluminal debulking often not attempted (local expertise) resulting in default tracheostomy which in turn can delay discharge (often little community support for patient with tracheostomies)	Few local protocols exist Decision making often made when patient in extremis by clinicians not involved in mainstream head and neck care	Cancer of the upper aerodigestive treact: assessment and management in people aged 16 and over. NICE NG36
29	Royal College of Speech & Language Therapists	Key area for quality improvement 5 Symptom management for patients referred for best supportive care	End of life care is an NHS priority and there is little evidence as to how to best support HNSCC patients who often have highly distressing symptoms	Again, services can be inconsistent	As far as the RCSLT are aware, there is minimal national data on patient access and utilisation of services

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
30	Royal College of Speech & Language Therapists	Key area for quality improvement 4 Timely post-treatment rehabilitation and survivorship interventions	These are crucial to patient quality of life, return to work etc.	There is inconsistent access to these services across England and these are considered a postcode lottery on whether patients receive them	DAHNO report on rehabilitation post-treatment assessments
31	SCM2	Consider early physiotherapy for shoulder impairment following neck dissection	Evidence to support the use of progressive resistance training improves function	Physiotherapy often not instigated in a proactive fashion Shoulder examination often not part of routine post-operative practice	Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over. NICE NG36
32	The Royal College of Radiologists	Specialist rehabilitation in Community	2016 NICE guidelines on UADT cancer management, recommended specialist nutritional and speech and language therapy and physiotherapy support. Patients undergoing radical treatment (surgical and non-surgical) for UADT cancer have significant morbidity and specialist intervention can significantly improve QOL without placing additional burden on hospital services.	The national head and neck cancer audit (http://www.hscic.gov.uk/catalogue/PUB14257/clin-audi-supp-prog-head-neck-dahn-12-13.pdf) that specialist allied health professional support is sub-optimal with wide national variation.	The initial evaluation of the **south-east London (**Community Head and Neck Team ,CHANT), (https://www.myhealth.london.nhs.uk/system/files/10.%20Community%20Head%20and%20Neck%20Team.pdf) including patient satisfaction surveys have demonstrated that this model of delivery improved patient satisfaction, quality of care and led to reduced burden on tertiary care services.
		Information and support			
33	SCM3	Provision of better information to patients with diagnosis of head and neck cancer throughout their	It is important to inform the patient about the complex nature of their treatment and outcomes in both the short-term and long term. The provision of patient information is also vital for informed consent.	Head and neck cancer is a complex set of diseases with varied treatment and follow up pathways. However, every patient will benefit from improved information tailored to their needs and delivered at critical points along their treatment pathway.	Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over

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		pathway.	The potential benefits include improved patient experience, better informed patients and carers, and the provision of specific information for patients with HPV-related cancers. This may potentially lead to information overload for some patients, which may lead to increased anxiety if the information is not tailored to the individual. However the majority of patients will benefit.		NICE guidelines [NG36] Published date: February 2016

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34	Royal College of Speech & Language Therapists	**Key area for quality improvement 3** Pre-treatment information on the potential effects of treatment are given	There is evidence that suggests good pre-treatment information helps to prepare patients, for major alterations, to life style and quality of life	This is a simple intervention, requiring multi-disciplinary input and may help improve the patient (and family) experience	Speech and language therapist's and dietitian's surveys on who sees patients pre-treatment **DAHNO report on pre-treatment assessment**
35	SCM5	Provision of a named CNS (or other designated key worker) and their contact details for every patient	Patients have been seen to value having a key worker such as a CNS, which makes care more patient-centred. Additionally it has proved to improve efficiency in many ways such as reducing the number of consultations with a doctor.	Two sources of evidence indicate room for improvement and also that patients with tumours at most other sites fare better than head and neck patients in this regard. The NCPES report reveals the % of patients given the name of a CNS, around 86% for head and neck patients. Successive NCPES reports show little change in the percentage of patients having a named CNS, with a small improvement of 2% in recent years. On the other hand there are indications patients have found contacting their key worker has become a little more difficult. The DAHNO reports present a different statistic - the % meeting a CNS before treatment decisions are finalised and this is currently approaching two thirds.	DAHNO Report 10 NCPES 2014
		Additional areas			
36	British HIV Association (NHIVA)	Key area for quality improvement 1	There really are very few HIV+ patients with these cancers and BHIVA has the following comments	Patients with head and neck cancer requiring chemotherapy or radiotherapy should be tested for HIV as per HIV malignancy guidelines (and treated if HIV+)	
37	British HIV Association (NHIVA)	Key area for quality improvement 2		Head and neck cancer patients with HIV should not be excluded from clinical trials because of their HIV status alone	

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38	ENT UK	Reform of the 2 week wait cancer referral criteria	The current and even the recently revised NICE 2 week wait criteria are extremely poor in identifying patients with a significant risk of H&N cancer. As a result a lot of time is lost as patients with no cancer risk are referred in to a tracked pathway, consuming imaging and diagnostic resources, which are not appropriate to their level of risk. This diverts resources from those with a higher risk and consumes specialist time putting pressure on theatre time and treatment planning.	Numerous audits and studies have identified that this is an increasing problem and almost no units are meeting the 31 and 62 day targets due to the abuse of the 2 week wait referral system. With each successive audit of the system the pick up rate drops but the numbers of patients seen increases as trusts increase capacity to meet the 14 day target.	Numerous published audits
39	SCM4	Suspected cancer referrals	The new NICE guidance seems to have excluded several important areas that should be referred as a 2 week wait	Potential cancers may be missed or referred late	Nice guideline 12
40	Merck Sharp & Dohme	**Key area for quality improvement 1** Early detection and diagnosis of Head and Neck cancers	As with any type of cancer, the prognosis for individual patients depends heavily on the stage of the disease at diagnosis.	More than half of head and neck cancers are diagnosed at an advanced stage (stage III/IV). [1,2] Moreover, head and neck cancers are unusual in that there appears to have been little improvement in survival rates over recent decades.[1,2] More effort is needed on early detection of head and neck cancers, given the poor outcomes associated with advanced disease.	1. Squamous Cell Carcinoma of the Head and Neck. Decision Resources Report. 2014.Available at https://decisionresourcesgroup.com/report/202/ Accessed June 2016. 2. National head and neck cancer audit 2012. Appendix 3. Available at: http://www.hscic.gov.uk/catalogue/PUB11015/clin-audi-supp-prog-head-neck-dahn-11-12-rep0.pdf Accessed June 2016.
41	Royal College of Speech &	Key area for quality improvement 1	For earlier referral to specialist services for diagnosis and treatment planning, and a	For earlier referral to specialist services for diagnosis and treatment planning, and a reduction	For earlier referral to specialist services for

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	Language Therapists	Early identification of head and neck cancer symptoms by GP and GDP	reduction in the number of patients referred with advanced stage head and neck squamous cell carcinoma (HNSCC)	in the number of patients referred with advanced stage head and neck squamous cell carcinoma (HNSCC)	diagnosis and treatment planning, and a reduction in the number of patients referred with advanced stage head and neck squamous cell carcinoma (HNSCC)

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42	Royal College of Speech & Language Therapists	Key area for quality improvement 2 Shared decision-making and treatment options which are offered, and where these are available	Because patients are central to decision making in their care and it is important that they are offered the most current treatment options	Surgical and oncological treatment options presented or patient offered best supportive care where appropriate	DAHNO should be referenced for trends in treatment options, or source geographical trends to see which treatments are offered in which locations
43	Merck Sharp & Dohme	**Key area for quality improvement 3** Ensure that information on local care services available and any choice within them is given to all patients at time of diagnosis.	Head and neck cancers can have devastating effects on the lives of patients and carers; the treatment can have a profound impact on the way the patient looks, talks, eats, or breathes, which can severely impact their overall quality of life.[6] Patients with head and neck cancer are at particular risk of psychological problems, particularly social anxiety and depression.[6] The quality of life of head and neck cancer patients could undoubtedly be enhanced by optimum treatment and the provision of adequate support and rehabilitation services (including specialist nurses, speech and language therapists, dietitians and clinical psychologists).[6]	For health services, head and neck cancers present particular challenges because of the complexity of the anatomical structures and functions affected, the variety of professional disciplines involved in caring for patients, and the relatively sparse geographical distribution of patients requiring specialised forms of therapy or support.[5] Patients with head and neck cancers need specialised support from a variety of therapists. However, NHS provision for these patients is not consistent; it varies from place to place and has been changing over recent years.[5]	3. Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over. NICE guideline (NG36). February 2016. Available at https://www.nice.org.uk/guidance/ng36 Accessed June 2016.
44	Merck Sharp & Dohme	**Key area for quality improvement 2** Increase public awareness of head and neck cancer	Public awareness of head and neck cancers is low, probably because of its relative rarity.[3] There is a clear need to inform and educate the public in matters relating to the known risk factors associated with head and neck cancers and potential signs or symptoms suggestive of head and neck cancers.[3]	A pan-European survey conducted in 2008 identified that the awareness of symptoms and risk factors for head and neck cancers in the UK lagged behind that in Europe.[4] A comprehensive health promotion strategy to reduce smoking and excess alcohol consumption is essential to halt increases in head and neck cancer trends.[5] In addition; public awareness may help earlier presentation, diagnosis and referral of head and neck cancers. The first source of delay in diagnosis and access to treatment is the delay	4. Warnakulasuriya KAAS, *et al*. An alarming lack of public awareness towards oral cancer.Br Dent J 1999; 187(6):319-322. 5. 'About Face' Head and Neck Cancer Awareness EU Omnibus Survey, TNS Healthcare September 2008. 6. National Institute for

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				between patients' awareness of symptoms of their cancer and visiting their general practitioner, which is usually about two to three months but can be years.[5]	Health and Clinical Excellence. Improving outcomes in head and neck cancers – the manual. London: NICE; November 2004.

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		Other information			
45	SCM2	Additional evidence sources for consideration	DAHNO / HANA ENT UK Head and Neck Cancer Multidisciplinary Guidelines		
46	NHS England	Additional evidence sources for consideration	• NHS England ***Implementing the cancer taskforce recommendations: commissioning person centred care for people affected by cancer*** Gateway reference 04312, April 2016 • NHS England ***Achieving World-Class Cancer Outcomes: Taking the strategy forward*** Five Year Forward View, May 2016		
47	The Society and College of Radiographers	Key area for quality improvement 1	Our only point at this stage is that other documents cited are now quite old although the general principles within them do apply • Improving outcomes in children & Young people with cancer (2005) • Improving outcomes in head and neck cancers (2004)		
48	Cochrane oral health		Cochrane Oral Health does not have a formal submission of recommended quality standards at this stage, but we would like to alert you to our reviews on oral cancer or oral problems caused by cancer treatment (attached). All of these were identified as priority topics when we conducted an oral health review prioritisation project. We received a comment from one of our authors on the quality standard. He said he was glad NICE will offer oral health promotion in care homes and hospitals and that this should include oral cancer care. He pointed out he could not see guidance on habits such as betel and		 Cochrane Oral Health Cancer Review

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			hooklahs.		
		No comments			
49	Royal College of Nursing	This is to inform you that the Royal College of Nursing have no comments to submit to inform on the above topic engagement at this time.			
50	Royal College of Paediatrics and Child Health	Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the *Head and neck cancer* consultation. We have not received any responses for this consultation.			