

**NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE**

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Head and neck cancer.

Date of quality standards advisory committee post-consultation meeting:

10 November 2016.

2 Introduction

The draft quality standard for head and neck cancer was made available on the NICE website for a 4-week public consultation period between 19 September and 14 October 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 22 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically

not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?
2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?
3. Do you have an example from practice of implementing the NICE guidelines that underpins this quality standard? If so, please submit your example to the [NICE local practice collection](#) on the NICE website. Examples of using NICE quality standards can also be submitted.
4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific question:

Question 5 For draft developmental statement 3: Does this reflect an emergent area of cutting-edge service delivery? If so, does this indicate outstanding performance only carried out by a minority of providers that will need specific, significant changes to be put in place, such as redesign of services or new equipment? Can you provide any examples of current practice in this area?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- General support for the quality standard.
- Quality standard could emphasise the importance of a team approach, including primary care dentists.
- Further centralisation of services is an area for change and this may follow based on the quality standard.
- Thyroid cancer should be included.

Consultation comments on data collection (question 2)

- Suggestion to include the quality standard in the national head and neck cancer audit (HANA) and a comment that more administration staff are needed to complete data collection.

Consultation comments on resource impact (question 4)

- No general comments received. Comments received for specific statements.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People with cancer of the upper aerodigestive tract have their need for enteral nutrition assessed at diagnosis.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- General support for statement.
- Assessment for enteral nutrition should already be happening in most head and neck units.
- Suggestion to reword statement to ‘...need for oral nutrition support and enteral tube feeding assessed...’ as enteral can be misinterpreted as only meaning tube feeding.
- Suggestion to reword the rationale to include more detail on risk of malnutrition and the reasons people may develop difficulties with eating and drinking.
- The audience descriptor should mention specialist dietician services rather than expecting teams to assess nutrition.
- The statement will be difficult to achieve as the posts needed (nutrition specialist nurse, dietitian and speech and language therapy service) are often unfilled.
- Suggestion to include the [nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition](#) (CG32) in the related NICE quality standards section.

Consultation comments on data collection (question 2)

Stakeholders made the following comments in relation to consultation question 2:

- There are systems in place to collect this data. The national head and neck cancer audit (HANA) collects data on the number of patients reviewed by a dietitian prior to commencing treatment.
- Outcome: ‘nutrition level’ is poor terminology. Suggestion to replace with ‘nutritional status’ and examples such as percentage weight loss or BMI.

- Suggestion to include [British Artificial Nutrition Survey](#) (BANS), a multi-professional Committee of the British Association for Parenteral and Enteral Nutrition (BAPEN), as a data source.
- Suggestion to include access to dietetic services as a quality measure as these services need to be provided to cancer centres to achieve the statement.

Consultation comments on resource impact (question 4)

Stakeholders made the following comments in relation to consultation question 4:

- There is a lack of specialist dietetic service in many areas meaning achievement of the quality statement could be difficult. However, the statement could help the case for additional specialist staff.

5.2 *Draft statement 2*

People with advanced stage cancer of the upper aerodigestive tract are offered systemic staging using fluorodeoxyglucose positron emission tomography (FDG PET)-CT.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- General support for statement.
- Sensible use of valuable imaging resource.
- Suggestion to expand the scope of the statement to include people with unknown head and neck cancer primary.
- Agreement that people needing FDG PET-CT should receive assistance to make the journey for this type of scan.

5.3 *Draft statement 3 (Developmental)*

People with early stage oral cavity cancer are offered sentinel lymph node biopsy.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Some support for the statement.
- Some concerns about the statement.
- Some clarity needed on whether all oral maxillofacial surgeons in head and neck units will do this and how it will be decided which units carry it out.
- Comment that there is no randomized controlled trial evidence supporting the use of sentinel lymph node biopsy (SLNB) for management of the neck in early stage oral cavity cancer.
- Disagreement that SLNB is a low morbidity procedure. In patients who have or develop metastatic neck disease SLNB results in increased morbidity and mortality. The majority of these patients fail to complete the treatment package (radiotherapy within 6 weeks of completion of surgical treatment) within the recommended time frame. Use of SLNB results in poorer outcomes in patients with aggressive oral cancer when compared with the gold standard.
- SLNB places an inappropriate emphasis on a small potential reduction in morbidity in those who do not develop metastatic neck disease.
- The survival advantage shown by the use of elective neck dissection to treat the node negative neck in oral cancer sets a gold standard.
- A statement offering SLNB outside a randomised prospective controlled trial will result in significantly increased mortality and morbidity.
- The Sentinel European Node Trial (SENT) suggests that SLNB in early stage oral cancer is safe and reliable.
- Suggestion to change the scope of the statement to squamous cell carcinoma staged 1 or 2 and >5mm where microvascular reconstruction is not needed.
- Patients needing microvascular free-tissue reconstruction will still undergo elective lymph node dissection for vascular access. In major head and neck centres, these patients are a major proportion of the workload.

- The statement is restrictive. SLNB for other head and neck cancer subsites is technically more challenging and the potential to drive forward standards of care with a move to include SLNB for all subsites is important.
- Suggestion to include grading in addition to size.

Consultation comments on data collection (question 2)

Stakeholders made the following comments in relation to consultation question 2:

- There is no HRG (healthcare resource group) code for head and neck SLNB so consistent data collection may be difficult.
- Support for the quality measure on the proportion of people who have SLNB as it will ensure reasonable uptake of the procedure.
- Suggested additional measures including proportion of patients with reduced post-operative length of stay and patient quality of life measures compared with elective neck dissection.

Consultation comments on resource impact (question 4)

Stakeholders made the following comments in relation to consultation question 4:

- This will require training of surgeons, radiologists and histopathologists and investment in equipment and will therefore take time to implement.
- Savings related to reduced inpatient stay and fewer complications should offset any initial expenditure in the long-term.
- There is no HRG code for head and neck SLNB which makes it difficult to estimate cost savings.
- There are cost implications for pathology services in the implementation of a full SLNB protocol and it is not clear where such finance would come from.
- This procedure will, at least initially, be carried out by a minority of providers, and centralised service provision may be an appropriate model of service delivery.

Consultation comments on developmental statement (question 5)

Stakeholders made the following comments in relation to consultation question 5:

- Agreement that this is an emergent area of cutting-edge service delivery.

- The statement has significant implications for oral maxillofacial surgeons in head and neck units.
- Significant service redesign, investment in new equipment and training will be necessary, particularly in head and neck units based in hospitals where no SLNB practices currently exist.
- Units already providing a head and neck SLNB service for melanoma could facilitate cross-functional working between surgical specialities for SLNB in oral cavity cancers. Significant changes may not be required for these units.

5.4 Draft statement 4

People with cancers of the upper aerodigestive tract that have similar outcomes from surgery or radiotherapy are given a choice of these treatment options.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Some support for the statement.
- Query about why the statement is limiting patient choice to people whose cancers have similar outcomes from surgery or radiotherapy.
- The statement should not include patients with T3 laryngeal cancers who should be offered an organ preservation approach (chemoRT) whenever possible.
- Comment that, due to waiting times for radiotherapy and its unquantifiable long term risks, this choice may not be something patients want.
- The statement should be future proof as these treatments may be superseded. It could refer to trans oral robotic surgery (TORS), intensity modulated radiotherapy (IMRT), proton beam radiation therapy (PBRT) and other techniques.

Consultation comments on data collection (question 2)

Stakeholders made the following comments in relation to consultation question 2:

- It is difficult to see how the suggested data collection can reliably measure whether choice has been offered or not.

Consultation comments on resource impact (question 4)

Stakeholders made the following comments in relation to consultation question 4:

- Having full discussions about options does take a certain amount of time which would have a resource impact.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Thyroid cancer - variable surgical skill in the UK and relatively high complication rates for recurrent laryngeal nerve injury and permanent hypoparathyroidism.
- Early diagnosis and referral, particularly general dental practitioners, to reduce late detection.
- Independent peer advocacy support.
- HIV testing prior to commencing treatment.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments ¹
		General comments	
1	British Association of Endocrine & Thyroid Surgeons		BAETS supports the guidelines for Thyroid Cancer care as published by the British Thyroid Association in 2014
2	Royal College of General Practitioners		This document provides a sensible and standard approach to a cancer which can be difficult to diagnose, treat and manage and where prognosis has altered little in 30 years. The importance of a team approach could be emphasised-Maxillo-facial surgeon, ENT surgeon, Oncologist, Radiotherapist, Dental Surgeon, Nutritionist, Plastic surgeon, Palliative Care physician, the need to determine a plan with patient and family with agreed time scales and benchmarks. The epidemiology suggests that lifestyle, neglect and poverty are important, for oral cancers betel nut chewing, leucoplakia and oral syphilis are also risk factors. The role of the dentist in referring non-healing ulcers rapidly for biopsy and assessment should be emphasised. (PS)
3	Royal College of Paediatrics and Child Health		We are happy this draft standard.
4	The Royal College of Pathologists		In general, we support this standard. There may be other places in which we might have placed emphasis but these selected areas seem sensible and achievable. Further centralisation of services would seem to be a further area for change and may follow some of these proposals (esp Pet-CT).
5	Royal College of Speech and language Therapists	Intro	The RCSLT believe the list of areas affected should include 'speaking or speech' so that is inclusive of those with reduced intelligibility
		Question 1	

¹ PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments ¹
6	British Association of Endocrine & Thyroid Surgeons		We feel that, in the consultation document produced by NICE, thyroid cancer should have its own chapter and not be subsumed within disparate chapters alongside squamous cancers of the upper aero-digestive tract. Such an independent chapter will have more relevance across the various clinical disciplines that treat patients with thyroid cancer.
7	British Association of Endocrine & Thyroid Surgeons		BAETS works closely with patient support groups relating to thyroid disorders. We have found that patients prefer thyroid clinics/clinical pathways to be separate to the clinics/pathways for patients with non-thyroid head and neck cancers.
8	British Association of Endocrine & Thyroid Surgeons		The UK registry for Endocrine and Thyroid Surgery (UKRETS) is the only HQIP approved registry for the mandatory collection of thyroid and endocrine surgery clinical outcomes. Data from UKRETS is made available in Consultant Outcomes Publications managed by NHS England. BAETS feels it is mandatory for all thyroid surgeons to enter their outcomes data into UKRETS for audit, quality control and openness and transparency.
9	British Association of Endocrine & Thyroid Surgeons		BAETS have collaborated with ENT-UK at the request of the CQC to produce a set of standards for thyroid surgery. These are attached for your information. Comments forms\British Association of Endocrine & Thyroid Surgeons and ENT info.pdf
10	British Dietetic Association (BDA) – Oncology Sub-group	Statement 1	Question 1: Yes
11	British Thyroid Foundation		We understand that thyroid cancer should be included as one of the key areas in this Quality Standard but note it is not referred to in the draft. We believe that the focus could be the variable surgical skill in the UK and the relatively high complication rates for recurrent laryngeal nerve injury and permanent hypoparathyroidism.
12	The Faculty of General Dental Practice (UK)		The Faculty of General Dental Practice UK (FGDP(UK)) is based at The Royal College of Surgeons of England. We provide a national voice for over 4,700 fellows and members. Around 95% of dental care in the UK is provided in the primary dental care setting. FGDP(UK) improves the standard of primary care dentistry delivered to patients through standard setting, postgraduate training and assessment, publications, policy development and research.
13	The Faculty of General Dental Practice (UK)		Does this draft quality standard accurately reflect the key areas for quality improvement?

ID	Stakeholder	Statement number	Comments ¹
			<p>The incidence of oral cancers in the UK has increased by 92% over the last 40 years, and 39% over the last decade. There were over 7,500 diagnoses in 2013, and with poor prognoses for late detections/presentations, almost 2,400 people died from oral cancers in 2014².</p> <p>Yet all the statements in the draft standard target treatment in quite advanced cases. As the standard aims to improve cancer survival rates in line with Domain 1 of the NHS Outcomes Framework 2016-17 (p2), it would seem logical for the standard also to target improvements in early detection.</p> <p>General Dental Practitioners are vital in this regard, as they examine the mouth and associated structures more frequently than General Medical Practitioners and other healthcare professionals, and there are countless examples of dentists referring lesions to specialist units, with high rates of positive diagnoses. However, as the draft excludes reference to early detection, there is nothing in it which will help the profession further contribute to much-needed improvement in this area.</p>
14	Royal College of Physicians and Surgeons of Glasgow	All	Denominator capture for all head and neck cancers and cancers by TNM class should be accurately recorded without any additional resource, via local MDT's. This mechanism is already in place. All Head and Neck Cancer should be recorded automatically.
15	Royal College of Speech and language Therapists		<p><i>Does this draft quality standard accurately reflect the key areas for quality improvement?</i></p> <p>Yes, the safety aspect of feeding as well as patient choice and acceptance of risk are addressed</p>
		Question 2 – general	
16	Royal College of Speech and language Therapists		<p><i>Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?</i></p> <p>The RCSLT enquire as to whether this could be included in HANA/national data collection tool? Also through access to peer review reports to ensure equality of access for all disciplines across the pathway, and not just what can be recorded at the MDT discussion meeting. Need to ensure/recruit more admin staff to do this and not clinician time.</p>
		Question 3 – general	
17	British Dietetic Association (BDA) –	Statement 1	Question 3: There are examples of good practice in this area e.g. multi-disciplinary pre-treatment assessment clinics within hospital Trusts.

² Figures from Cancer Research UK website, accessed on 13/10/2016, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oral-cancer>

ID	Stakeholder	Statement number	Comments ¹
	Oncology Sub-group		
18	Norgine Pharmaceuticals Ltd.	Quality Statement 3	<p>Can you provide examples of current practice in this area?</p> <p>Queen Victoria Hospital NHS Foundation Trust have recently set up a SNLB service for oral cavity cancer¹. We are also aware of three established centres providing SLNB service for head and neck, in oral cavity SCC: Guy's and St.Thomas' Hospital (we understand this is in the process of being migrated to UCL), Aintree Hospital Liverpool and Queen Elizabeth Hospital, Glasgow. Oxford and Coventry have just started their SLNB services for oral cavity cancer. We are also aware of SLNB in head and neck undertaken for malignant melanoma at the following centres: Hull, Leeds, Norwich, Manchester, Liverpool, Newcastle, Cambridge, Oxford, London (Guy's & St.Thomas, St.George's), Guildford, Poole and Southampton. There are likely to be many more plastic surgery and OMFS units providing an SLNB service for melanoma.</p> <p>(1) NICE 2016 Setting up a service for sentinel lymph node biopsy in patients with early oral squamous cell carcinoma https://www.nice.org.uk/sharedlearning/setting-up-a-service-for-sentinel-lymph-node-biopsy-slnb-in-patients-with-early-oral-squamous-cell-cancer-scc-our-experience-to-date (Accessed 10/10/2016)</p>
19	The Royal College of Pathologists	3	Request for examples: The service currently provided by the Head and Neck Pathology service at Guys Hospital may be appropriate. They have been achieving this standard for many years.
20	Royal College of Speech and language Therapists		<p><i>Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard?</i></p> <p>We would like to suggest that there will be evidence from peer review and there is a need to have more links with this team.</p>
		Statement 1	
21	British Association of Oral and Maxillofacial Surgeons (BAOMS)		<ul style="list-style-type: none"> Assessment for enteral nutrition should already be happening in most head and neck units.
22	British Dietetic Association (BDA) – Oncology Sub-group		We recommend that this statement should read ' People with cancer of the upper aerodigestive tract have their need for oral nutrition support and enteral tube feeding assessed at diagnosis'. The term enteral by itself is problematic as it can be misinterpreted as relating only to tube feeding. We know from DAHNO data that a significant number of H&N cancer patients require tube feeding (47% patients) however a large amount also require oral nutrition support (~38%). The quality standard should therefore include oral and tube feeding such that nutrition support as a whole is considered at diagnosis.

ID	Stakeholder	Statement number	Comments ¹
			NB: The terminology would then need to be changed throughout the whole document if agreed, wherever enteral is mentioned.
23	British Dietetic Association (BDA) – Oncology Sub-group		Rationale: a better statement here might be: ‘People with cancer of the UADT are at risk of malnutrition at diagnosis due to the site of the disease as well as pre-existing dietary habits. Further patients will develop difficulties with eating and drinking during treatment or the course of their disease which will further negatively impact on nutritional status. Assessing the need for oral and enteral nutrition support at the time of diagnosis will ensure adequate nutrition before, during and after treatment. (And then final sentence in this bit to stay the same).
24	British Dietetic Association (BDA) – Oncology Sub-group	Statement 1 What the quality statement means for service providers, healthcare professionals and commissioners Page 8	There needs to be a mention of specialist dietitian services in this section (rather than expecting teams to assess for nutrition).
25	British Dietetic Association (BDA) – Oncology Sub-group	Related NICE quality standards Page 24	Should reference the following published NICE guideline: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition (CG32) (NICE 2006)
26	Cancer National Specialist Advisory Group		Quality indicators 1 and 2 – accepted, no comments
27	Royal College of Physicians and Surgeons of Glasgow		Analysis of local QPI’s suggest that whilst this statement should be met, and is a fundamental component in the treatment of patients undergoing both radical treatment and those for supportive care only, it is rarely achieved. Sadly, the nutrition specialist nurse, dietitian and speech language therapy service posts which are essential for this aspect of patient care are frequently unfilled. Services are spread too thinly, and targets become impossible. We believe that this standard will be difficult to achieve, unless there is a wholesale change in the attitude of organisations to the appointment of the relevant staff. However, it is an important, highly laudable standard to set.
		Question 2 – statement 1	

ID	Stakeholder	Statement number	Comments ¹
28	British Dietetic Association (BDA) – Oncology Sub-group		Question 2: There are systems in place to collect data for this quality standard – DAHNO and now HANA, collect information on number of patients reviewed by a dietitian prior to commencing treatment. Patients reviewed will have had their need for oral nutrition support and enteral tube feeding assessed.
29	British Dietetic Association (BDA) – Oncology Sub-group		Outcomes: Nutrition levels is poor terminology, suggest better referred to as ‘nutritional status’ with or without list of what these could be (e.g. % weight loss/BMI/ grip strength/ meeting estimated requirements/adherence to agreed regimen/ preventing further significant weight loss).
30	Nutricia Advanced Medical Nutrition	Quality measures	<p>Consider the inclusion of British Artificial Nutrition Survey (BANS), a multi-professional Committee of BAPEN, as a data source for this quality standard. In 2011, a national survey of home enteral tube feeding for Head & Neck cancer patients was completed and published in the annual report. This survey aimed to determine the following:</p> <ul style="list-style-type: none"> <input type="checkbox"/> What is the prevalence of dietetic provision for HNC patients receiving radiotherapy? <input type="checkbox"/> How are HNC patients that require tube feeding identified? <input type="checkbox"/> What type of enteral feeding tubes do the majority of HNC patients have placed? <input type="checkbox"/> Are the majority of tubes prophylactic or reactive? <input type="checkbox"/> How is malnutrition identified before, during and after radiotherapy treatment in HNC patients? <p>Repetition of such surveys may assist in capturing:</p> <ul style="list-style-type: none"> - Evidence of local arrangements and written clinical protocols to ensure that people with cancer of the upper aerodigestive tract have their need for enteral nutrition assessed at diagnosis - Proportion of people with cancer of the upper aerodigestive tract who have their need for enteral nutrition assessed at diagnosis - Nutrition levels for people with cancer of the upper aerodigestive tract. <p>More information can be found on the website: http://www.bapen.org.uk/about-bapen/committees-and-groups/british-artificial-nutrition-survey</p>
31	Nutricia Advanced Medical Nutrition	Quality measures	The results of the 2011 BANS national survey of home enteral tube feeding for Head & Neck cancer patients indicate that only 18 Cancer Centres (51.4%) who responded had specific dietetic funding to support HNC patients. A Dietitian would be an important part of the MDT to complete the assessment of people’s need for enteral nutrition at diagnosis, specifically for the completion of an assessment of current nutritional status. To meet this quality standard, the provision of dietetic services to cancer centres will be important and, as such, suggestion to include access to dietetic services as one of the quality measures.

ID	Stakeholder	Statement number	Comments ¹
		Question 4 – statement 1	
32	British Dietetic Association (BDA) – Oncology Sub-group		Question 4: There are resourcing issues for specialist H&N dietitians in some regions within the NHS. (Lack of specialist dietetic services). This could make achievement of the quality standard problematic but could equally help the case for additional specialist staff.
		Statement 2	
33	British Association of Oral and Maxillofacial Surgeons (BAOMS)		<ul style="list-style-type: none"> • Sensible use of valuable imaging resource.
34	Royal College of Physicians and Surgeons of Glasgow		For the sake of clarity, the scope of this statement should be expanded to include patients with an unknown primary Head and Neck Cancer. Whilst NG36 contains a guideline strongly advocating FDG PET availability for UPHNC, all of the relevant indications should be included in the standard. The word ‘consider’ in relation to FDG PET scanning should be removed from NG36, to allow development of diagnostic algorithms which shorten the wait for MDT assessment. An expectation that FDG-PET will be undertaken should help the drive change in somewhat cumbersome diagnostic pathways.
35	The Society and College of Radiographers		<p>Page 12, Equality & diversity considerations.</p> <p>There can be significant travel required due to the geographic variation in availability of FDG PET – CT. The Society and College of Radiographers supports the statement that this should be available for people with advanced stage cancer of the upper aerodigestive tract. We also support that people needing this type of scan should be assisted to make the journey for this type of scan - however this patient group would have significant challenges given the advanced nature of the disease so we would be in support of a statement to enable more local provision of PET – CT scanners where possible.</p>
		Statement 3	
36	British Association of Oral and Maxillofacial Surgeons (BAOMS)		<ul style="list-style-type: none"> • Potential concerns: <ul style="list-style-type: none"> ○ Will all OMF surgeons working in head and neck units provide this service? ○ Who decides which head and neck units undertake sentinel node biopsies? ○ Will there be funding to support new equipment? ○ Will there be a reduction in the number of head and neck units and is this the intention of the document? ○ Is there substantive evidence to support this change in practice?

ID	Stakeholder	Statement number	Comments ¹
37	British Association of Oral and Maxillofacial Surgeons (BAOMS)		perhaps a better option will be :- SCC clinically staged 1 or 2, and >5mm, but with proviso of no requirement for microvascular reconstruction.
38	British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS)		The Sentinel European Node Trial (SENT) suggests that sentinel node biopsy in early stage oral cancer is safe and reliable. BAPRAS would support its wider implementation in the United Kingdom, but this will require rigorous training of surgeons, radiologists, and histopathologists, as well as investment in the necessary equipment. At present only a few head and neck units in the UK offer sentinel biopsy for head and neck cancer, and it would appear to make sense initially to restrict such specialised services to units with a high patient throughput. It must be stressed that patients who require microvascular free-tissue reconstruction will still undergo elective lymph node dissection for vascular access. In major head and neck centres, such patients can form a major proportion of the workload.
39	Cancer National Specialist Advisory Group		QI 3 – sentinel node biopsy – there is no randomized controlled evidence supporting the use of SNB for management of the neck in early stage oral cavity cancer. As such, I believe it's inappropriate to make offering a SN service to patients a quality indicator. Instead, it would be better for us to be encouraged to participate in UK clinical trials of SNB if and when they become available. I believe a better indicator would be the proportion of early stage oral cavity cancer patients who undergo surgery to the neck (either selective node dissection or SNB). I think that's consistent with the 2016 NICE guidelines and Kumar's 2015 NEJM paper (and whilst I realize that USS surveillance of the neck may be an option for patients with tumours <3-5mm in depth, that is not (yet) to my knowledge backed up by good clinical trial evidence).
40	Guy's hospital head and neck MDT	Statement 3 (People with early stage oral cavity cancer are offered sentinel lymph node biopsy. Domain 1 (NHS outcome framework 2016-2017)	As the UK centre with the largest experience of sentinel node biopsy in patients with oral cancer the head and neck MDT at Guy's have concerns in relation to a number of aspects of the NICE Quality Standard for head and neck cancer (September 2016). The gold standard for managing the node negative neck in oral cavity cancer has recently been defined in a prospective randomised control trial published in the NEJM (6/8/2015) (1). This identified an overall survival benefit of 12.5% and a disease free survival benefit of 23.6% from treating the node negative neck with an elective neck dissection, in clinical practice where surveillance protocols have less fidelity the benefits are likely to be even greater. In contrast sentinel node patient biopsy performed at GSTT has a 13%-14% (2,3) false negative rate and an intense follow up protocol consistent with that utilised by De Cruz et al has had to be institute to mitigate decreased survival in patients requiring salvage neck dissection after a negative sentinel node biopsy. 1 - D'Cruz AK, Vaish R, Kapre N, Dandekar M, Gupta S, Hawaldar R, Agarwal JP, Pantvaidya G, Chaukar D, Deshmukh A, Kane S. Elective versus therapeutic neck dissection in node-negative oral cancer. New England Journal of Medicine. 2015 Aug 6;373(6):521-9.

ID	Stakeholder	Statement number	Comments ¹
			<p>2- Schilling C, Stoeckli SJ, Haerle SK, Broglie MA, Huber GF, Sorensen JA, Bakholdt V, Krogdahl A, von Buchwald C, Bilde A, Sebbesen LR. Sentinel European Node Trial (SENT): 3-year results of sentinel node biopsy in oral cancer. European Journal of Cancer. 2015 Dec 31;51(18):2777-84.</p> <p>3 - Correspondance Professor Mark McGurk UCL with GSRR NHS Trust 28th September 2016</p>
41	Guy's hospital head and neck MDT	Statement 3 (People with early stage oral cavity cancer are offered sentinel lymph node biopsy.	<p>Our institutional data has demonstrated an increased rate of significant and permanent complications in patients requiring neck dissection after a positive sentinel node biopsy. Only 10% of patients received this treatment within 2 weeks, and infact 39% of patients waited more than 28 days. Complications include sacrifice Internal Jugular Vein (3 patients), Spinal Accessory Nerve damage (2 patients), Haematoma (2 patients, 1 return to theatre), Chyle leak (4 patients, 2 requiring VATS ligation), Vocal cord palsy (2 patients), Marginal mandibular nerve weakness (2 patients), Seroma (2 patients), Wound infection (2 patients), Transection Vagus nerve (1 patient), Transection Hypoglossal nerve (patient). This data has been presented nationally (4). We therefore contest the view that SNB represents a low morbidity procedure. On further scrutiny of the literature we have found proponents of SNB to exclude the patients with positive nodes requiring completion neck dissection from their analysis of complications.</p> <p>4 - BAHNO Annual Scientific Meeting 2016, 13.5.2016 - Royal College of Physicians. Oral presentation.</p> <p>5 - Audit of complications of completion neck dissections following positive sentinel node biopsy - GSTT head and neck meeting 14.04.2016</p>
42	Guy's hospital head and neck MDT	Statement 3 (People with early stage oral cavity cancer are offered sentinel lymph node biopsy.	<p>The majority of SNB patients requiring a neck dissection failed to receive radiotherapy within 6 weeks of their completion of surgical treatment, breaching national standards of patient care (5).</p> <p>5 - Audit of complications of completion neck dissections following positive sentinel node biopsy - GSTT head and neck meeting 14.04.2016</p>
43	Guy's hospital head and neck MDT	Statement 3 (People with early stage oral cavity cancer are offered sentinel lymph node biopsy.	<p>In summary we feel given the recent survival advantage demonstrated by the use of Elective Neck Dissection to treat the node negative neck in oral cancer sets a clear gold standard.</p> <p>Our evidence would suggest that any NICE recommendation that Sentinel node biopsy should be offered to such patients outside the confines of a randomised prospective controlled trial is likely to result in a significant increase in mortality and morbidity. Sentinel node biopsy places an inappropriate emphasis on a small potential reduction in morbidity, for which there is no published evidence, in patients with an excellent prognosis ie those who do not develop metastatic neck disease. However in patients who have or develop metastatic neck disease it results in increased morbidity and mortality. The majority of these patients fail to complete the treatment package within the recommended time frame. Use of sentinel node biopsy results in poorer outcomes in patients with aggressive oral cancer when compared with the gold standard. This is entirely inconsistent with the NHS outcome frameworks objective.</p>

ID	Stakeholder	Statement number	Comments ¹
44	Norgine Pharmaceuticals Ltd.	Quality Statement 3 Equality and Diversity considerations page 16	We believe that over time, with the necessary training and service re-designs in place, a SLNB service should be offered in all tertiary head and neck units, and the majority of secondary units, to ensure patients do not have to travel significant distances to receive this procedure. Such journeys increase anxiety and inconvenience, and if the episode results in an overnight or longer stay at hospital, this will be far away from home. There is evidence to suggest patients make treatment choices based on what is available within their local health economy, and such patients would be disadvantaged because of a lack of available service within a reasonable travelling distance. Therefore, all eligible patients should be offered the procedure and supported to make the journey, but more importantly, all local health economies should consider the service re-design required to establish SLNB in their respective areas, to ensure patients are not indirectly disadvantaged in access to the service simply based on their location.
45	Royal College of Physicians and Surgeons of Glasgow		The indications for SNB in the standard are restrictive. SNB for other HNC subsites is technically more challenging due to access restrictions in delivering the isotope injection, but is of equal negative predictive value. As the indications for robotic surgery are expanded, the value of SNB to the treating surgeon increases. If access surgery is undertaken for blood vessel ligation prior to TORS, then the opportunity for morbidity limiting SNB arises. The potential to drive forward standards of care with a move to include SNB for all subsites is important.
46	Royal College of Speech and language Therapists	Definitions of terms Page 16	The RCSLT would like to point to a recent article (Otolaryngology – HNS, Oct 2016) which suggests both the size of tumour and grade of differentiation are important in this discussion. Does grading need to be stated in addition to size? Efficacy of Elective Neck Dissection in T1/T2N0M0 Oral Tongue Squamous Cell Carcinoma: A Population-Based Analysis (Tapan D, et al.)
		Question 2 - Statement 3	
47	Norgine Pharmaceuticals Ltd.		Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place? For H&N SLNB there is no HRG code. Consistent data collection may be impaired as a consequence.
48	Norgine Pharmaceuticals Ltd.	Quality Measures – Process page 14	<i>‘The proportion of people with early stage oral cavity cancer who have sentinel lymph node biopsy.’</i> We strongly support this quality measure since it will be key to ensure all eligible patients are not only offered the procedure, but that there is a reasonable uptake for the procedure that isn’t limited for non-clinical reasons e.g. geography and availability of service locally (as above)
49	Norgine Pharmaceuticals Ltd.	Quality Measures – Outcomes page 15	We would suggest considering the following outcome measures in addition: <ul style="list-style-type: none"> - Proportion of patients with reduced post-operative length of stay versus Elective Neck Dissection - Patient quality of life (QoL) measures versus Elective Neck Dissection - Physiotherapy requirements versus Elective Neck Dissection
		Question 4 - Statement 3	

ID	Stakeholder	Statement number	Comments ¹
50	British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS)		BAPRAS would support its wider implementation in the United Kingdom, but this will require rigorous training of surgeons, radiologists, and histopathologists, as well as investment in the necessary equipment. Savings related to reduced inpatient stay and fewer complications should offset any initial expenditure in the long-term, however.
51	Norgine Pharmaceuticals Ltd.		<p>Do you think this statement is achievable by local services given the net resources needed to deliver them? Describe any resource requirements that you think would be necessary. Describe any potential cost-savings or opportunities for disinvestment.</p> <p>The recently published NICE guideline on cancer of the upper aerodigestive tract estimated the cost-effectiveness of SLNB for the management of clinically and radiologically N0 Neck in comparison other management strategies. This analysis found that SLNB was cost-saving compared to Elective Neck Dissection over a ten-year time horizon (£9175 vs 9509)².</p> <p>This analysis highlighted a lack of high quality data for the estimation of SLNB costs. An absence of a HRG code for SLNB in head and neck cancer presents resulted in NICE using the code for intermediate breast procedure. The lack of appropriate coding for head and neck SLNB has two implications:</p> <ul style="list-style-type: none"> - Challenges estimating the cost-saving associated with head and neck SLNB - There is no code for recording activity. Consequently, local data collection may vary across the country <p>(2) NICE 2016. Cancer of Upper Aero-digestive Tract, NICE Guideline (NG36)</p>
52	The Royal College of Pathologists		The move towards Sentinel Lymph Node Biopsy as standard of care is welcome. However, there are a number of resource issues in relation to widespread implementation of the standard. There is a learning curve for both surgeons and pathologists that need to be taken into account, such services could not suddenly be provided and may not be appropriate for centres treating small numbers of cases. Additionally, there are cost implications for Pathology services in implementation of a full SLNB protocol (less so on the surgical side as much of the equipment needed will likely be available in centres where breast cancer and melanoma care is provided). It is not clear where such finance would come from. It is likely that this is a procedure that will, at least initially, be carried out by a minority of providers, and centralised service provision for this may be an appropriate model of service delivery
		Question 5 - Statement 3	
53	British Association of Oral and Maxillofacial		significant redesign of service and equipment is necessary.

ID	Stakeholder	Statement number	Comments ¹
	Surgeons (BAOMS)		
54	British Association of Oral and Maxillofacial Surgeons (BAOMS)		significant implications for OMF surgeons in head and neck units.
55	Norgine Pharmaceuticals Ltd.		<p>Does this represent an emergent area of cutting-edge service delivery?</p> <p>Sentinel lymph node biopsy (SLNB) is an emergent area of cutting-edge service delivery for oral cavity cancer. However, SLNB is a well-established technique amongst breast surgeons at axillary sites for breast cancer and amongst plastic surgeons at axillary and inguinal sites for malignant melanoma. In the latter group, SLNB is also used in the head and neck setting for detecting neck metastases for malignant melanoma.</p>
56	Norgine Pharmaceuticals Ltd.		<p>If so, does this indicate outstanding performance only carried out by a minority of providers that will need specific, significant changes to be put in place, such as re-design of services or new equipment?</p> <p>There are several units and various speciality groups with established competency, protocols and service delivery models for using this procedure for breast cancer and melanoma, as well as specifically for head and neck. Units already providing a head and neck SLNB service for melanoma could facilitate cross-functional working between surgical specialities for SLNB in oral cavity cancers, as these surgeons will already be collaborating within the Head and Neck MDT setting. For such units, significant changes may not be required as the basic infrastructure is already established through SLNB undertaken by plastic surgeons.</p> <p>However, as per the equality statement, all patients should have equitable access to such a service. Ideally this should be 'closer to home' and so, for those other head and neck units based in hospitals where no SLNB practices currently exist, service re-design may be required to ensure that there is an appropriate pathway and collaboration between pathology, nuclear medicine, radiopharmacy and surgical departments. Investment in new equipment may be required, such as intra-operative gamma probes and appropriate radiotracers.</p> <p>SLNB in the head and neck is reported to be technically complex, operator-sensitive and involves a learning curve – therefore, surgeons with no experience of the technique would require additional training. In addition, we would recommend that all units use the best available technology and appropriate radiotracers to ensure desired patient outcomes, particularly in maintaining a low false negative rate, which is critical for patient benefit.</p>
57	The Royal College of Pathologists		It is clearly an emerging area for cutting edge services in head and neck cancer.
		Statement 4	

ID	Stakeholder	Statement number	Comments ¹
58	Cancer National Specialist Advisory Group		<p>Q14 – choice of treatment – I don't agree with the statement in both the 'quality statement' and 'rationale' sections that says 'People with cancers of the upper aerodigestive tract that have similar outcomes from surgery and radiotherapy should be told about what these treatments involve' without defining who these people are. There are no good published RCTs of surgical vs non-surgical treatments for the management of HNSCC and the choice of treatment depends on available non-randomised data, functional outcome data and multiple patient and tumour factors. I agree that patients with T1-2 glottic, supraglottic and oropharyngeal cancers should be offered both treatments equally but not patients with T3 laryngeal cancers who (based on the available evidence) should be offered an organ preservation approach (chemoRT) whenever possible.</p>
59	Royal College of General Practitioners		<p>Statement 4 belongs in secondary care, but from a general perspective three related areas invite some comment:</p> <ol style="list-style-type: none"> 1. Is choice actually what patients want? With the waiting times for radiotherapy coupled with unquantifiable long term risks of radiotherapy this will be very hard to measure. We are only now recognising the effects on the heart from radiotherapy for breast cancer. (JS) 2. Why is patient choice limited to those patients where cancers have similar outcomes from surgery or radiotherapy? While it does not exactly state this, the statement implies that patients should be offered a choice when there is equipoise and not at other times. NICE should by now have accepted the principle of shared decision making, and be keen that patients should express preferences under all but exceptional circumstances (such as, for instance, when judgement is impaired, patients are unconscious, etc.). For some specialists it may be hard to offer choice when, in their view, there is a clear advantage of one modality over another. But that is to disregard the importance of patients' values, experiences, perception of risk etc. One way of reframing this statement is that NICE seems to be saying there should be patient choice where there is genuine equipoise, but not under any other circumstances; specialists should make the decision where the evidence points in one way; patients should decide when the specialists don't have an answer. It does encourage specialists to be honest about equipoise, but it risks them abandoning their responsibility to help patients make a decision when that happens. This presents NICE with an opportunity to encourage a general move to more shared decision making. Advising that it only applies with some conditions is missing that opportunity, but also requiring clinicians to remember when they are and are not supposed to be involving patients in decision making. This is asking for underachievement. 3. There is an actual difficulty that all clinicians have in managing to present options to patients with complete neutrality. There are in the literature plenty of examples where the framing of the evidence presented to patients is a powerful determinant of the choice that patients will eventually make, particularly the way that side effects are presented. This is not a reason for abandoning the principle, but it may help clinicians to acknowledge that we all find it difficult to express risks and benefits of different treatments as neutrally as we might wish. (DJ)
60	Royal College of Physicians and Surgeons of Glasgow		<p>It is interesting to note the wide range of applications of this standard. That is to say: Head and Neck Cancer has a limited range of treatments and a large number of unanswered questions. The standard should have an element of future proofing, especially if the implementation date is envisaged to be 2017, as it may find itself providing standards for treatments which have already been superseded. The standard could make reference to TORS, IMRT, PBRT and</p>

ID	Stakeholder	Statement number	Comments ¹
			other mucosal/salivary sparing techniques, which change the equipoise point in treatment decisions of this type. In particular, recent robust evidence suggests that a survival advantage is seen in large volume T3 and T4 laryngeal tumours treated with surgery and radiotherapy rather than organ preservation techniques, rather than the equivalence of treatments alluded to in the standard.
61	Royal College of Speech and language Therapists	4 p20	The RCSLT suggest moving the four areas at the bottom of page 29 Statement to the top under the 'what the quality statement means for patients'. For example; 'People with early stage cancer of the vocal cords (and other areas) are told... which of these treatments is best for them'.
62	The Society and College of Radiographers		Page 17, Quality measures – structure (a) The Society and College of Radiographers strongly supports the requirement for local arrangements and written protocols to ensure that people with cancers of the upper aerodigestive tract that have similar outcomes from surgery or radiotherapy are given the appropriate level of information and choice of treatment options as soon as possible in the pathway.
		Question 2 – statement 4	
63	Royal College of General Practitioners		4. Following on the above, it is difficult to see how the suggested data collection can reliably measure whether choice has been offered or not. Relying on patient notes is not enough, and there is the risk of clinicians reporting offering choice in order to conform to the standard without taking the time to explore the different options in any depth. The patient survey is also likely to be unreliable, depending on patients' prior perceptions of what constitutes choice, how they understood what was presented to them etc. One possibility is that clinicians could say clearly to the patients that they were now going to offer a choice, then present the evidence in such a way a choice was effectively denied. In order to measured this it may be necessary that consultations are observed by a third party, which is wholly unrealistic.
		Question 5 – statement 4	
64	Royal College of General Practitioners		5. The document asks specifically about resources needed to meet the statement. Having sensible discussions about options does take a certain amount of time, although it would be much appreciated to provide any studies that have attempted to quantify it. I would draw your attention to a recent article in the BMJ that emphasises that these kind of discussions should be given much more weight by medical staff (Medicine's solemn moments. Daniel Sokol. BMJ 2016; 354: i4380) (DJ)
		Additional areas	
65	British HIV Association		Need to test for HIV prior to commencing chemotherapy or radiotherapy (BHIVA guidelines for HIV-associated malignancies 2014, HIV Medicine (2014), 15 (Suppl. 2), 1–92.), as these cancer treatment modalities both have profound effects on CD4 counts. If the HIV is not diagnosed and treated and suitable prophylaxis given, patients will die from opportunistic infections and the cancer treatment will have contributed to these deaths.

ID	Stakeholder	Statement number	Comments ¹
66	British Association of Endocrine & Thyroid Surgeons		We feel that, in the consultation document produced by NICE, thyroid cancer should have its own chapter and not be subsumed within disparate chapters alongside squamous cancers of the upper aero-digestive tract. Such an independent chapter will have more relevance across the various clinical disciplines that treat patients with thyroid cancer.
67	British Association of Endocrine & Thyroid Surgeons		BAETS works closely with patient support groups relating to thyroid disorders. We have found that patients prefer thyroid clinics/clinical pathways to be separate to the clinics/pathways for patients with non-thyroid head and neck cancers.
68	British Association of Endocrine & Thyroid Surgeons		The UK registry for Endocrine and Thyroid Surgery (UKRETS) is the only HQIP approved registry for the mandatory collection of thyroid and endocrine surgery clinical outcomes. Data from UKRETS is made available in Consultant Outcomes Publications managed by NHS England. BAETS feels it is mandatory for all thyroid surgeons to enter their outcomes data into UKRETS for audit, quality control and openness and transparency.
69	British Association of Endocrine & Thyroid Surgeons		BAETS have collaborated with ENT-UK at the request of the CQC to produce a set of standards for thyroid surgery. These are attached for your information. Comments forms\British Association of Endocrine & Thyroid Surgeons and ENT info.pdf
70	British Thyroid Foundation		We understand that thyroid cancer should be included as one of the key areas in this Quality Standard but note it is not referred to in the draft. We believe that the focus could be the variable surgical skill in the UK and the relatively high complication rates for recurrent laryngeal nerve injury and permanent hypoparathyroidism.
71	The Faculty of General Dental Practice (UK)		Does this draft quality standard accurately reflect the key areas for quality improvement? The incidence of oral cancers in the UK has increased by 92% over the last 40 years, and 39% over the last decade. There were over 7,500 diagnoses in 2013, and with poor prognoses for late detections/presentations, almost 2,400 people died from oral cancers in 2014 ³ . Yet all the statements in the draft standard target treatment in quite advanced cases. As the standard aims to improve cancer survival rates in line with Domain 1 of the NHS Outcomes Framework 2016-17 (p2), it would seem logical for the standard also to target improvements in early detection. General Dental Practitioners are vital in this regard, as they examine the mouth and associated structures more frequently than General Medical Practitioners and other healthcare professionals, and there are countless examples of dentists referring lesions to specialist units, with high rates of positive diagnoses. However, as the draft excludes

³ Figures from Cancer Research UK website, accessed on 13/10/2016, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oral-cancer>

ID	Stakeholder	Statement number	Comments ¹
			reference to early detection, there is nothing in it which will help the profession further contribute to much-needed improvement in this area.
72	Older People's Advocacy Alliance (OPAAL) UK	2, 3, 4 (Briefing paper 4.4.2 Information & support)	The statement at 1.1.3 is insufficient: "Give people details of peer support services that can help them throughout their care pathway." It is vital that patients with neck and head cancer are offered not just a leaflet but an explanation as to why such services might be useful. Evidence from OPAAL's Cancer, Older People and Advocacy programme indicates that the person offering the initial information about a peer support service needs to understand what the benefits are to allow them to explain those potential benefits to the patient. Leaflets in themselves simply add to the pile of information that older people in particular find overwhelming. There is an obvious need to provide staff training on what independent peer advocacy is and what it can do to support the patient. Distribution of leaflets is not, in itself, enough.
73	Older People's Advocacy Alliance (OPAAL) UK	2, 3, 4 (Briefing paper 4.4.2 Information & support)	<p>Independent peer advocacy support is offered to older people with neck and head cancer in very few areas in England and Wales, currently 10 in England and 1 in Wales. The benefits in these areas cannot however be underestimated. Evidence produced as part of OPAAL's Cancer, Older People and Advocacy programme includes real life stories such as that of 57-year-old Suzanne who had been diagnosed with malignant cancer in her jaw, glands and neck.</p> <p>"I didn't want to see or speak to anyone, people thought I was mentally impaired when they met or spoke to me on the phone. I needed a voice and Lisa (her peer advocate) provided that along with the support I needed to regain some of my confidence back.</p> <p>I can only hope that in the future the district nurses, GP practises and Macmillan make sure that the much needed information, about places and people to contact to provide much needed help and support are made available from the beginning of someone's diagnosis. I'm really happy about my story being told as this is something I wanted to do. I want people to understand how lost I was before Lisa. Everyone should have access to someone like Lisa. Someone who makes all the difference."</p> <p>OPAAL also heard Charlie's story: He'd been a hospital inpatient for 9 months as he was still being fed through a PEG (a line straight into his stomach) after radiotherapy to treat throat cancer. He hadn't been able to return home as an appropriate Care Package had failed to be put in place. Although he was free to leave during the day, he had to spend the night on the ward while the liquid feed was slowly fed into his stomach. Charlie's future was far from certain when Karen (his advocate) first met him, he'd had radiotherapy to treat his throat cancer but there was no definitive prognosis. Karen attended appointments with him and his partner (and latterly wife) Pat.</p> <p>Karen supported Charlie at appointments, reminding him, ensuring hospital transport was in place and liaising as requested with health care professionals to ensure that he understood what was happening. She ensured he was supported to return to being able to eat some foods as soon as possible rather than taking all his nutrition via the PEG. Once Charlie's diagnosis became terminal, the focus of the advocacy centred on supporting him to stay in control of his life right to the end. Charlie desperately wanted to leave hospital and Pat and Charlie wanted to finally get married. The advocate was able to represent Charlie to both the Deputy administering the Power of Attorney and his Social Worker to facilitate not only these wishes but also his wish to die at home.</p>

ID	Stakeholder	Statement number	Comments ¹
			<p>Karen helped Charlie and Pat get appropriately graded on the housing list and successfully bid on a two bedroomed bungalow.</p> <p>Karen's challenge to the attitudes Charlie encountered from some health and social care professionals meant that his wishes were respected and that, in spite of them not necessarily understanding his decisions, they were respected." These are prime examples of the benefits to individuals of independent advocacy support and ensuring that informed decisions are made and the patient's voice is heard in all matters surrounding their care. It is OPAAL's belief that NICE Quality Standards should overtly call for the universal provision of independent peer advocacy support to ensure optimum opportunity for a positive patient experience. Whilst this does have resource implications for the NHS we see potential for major cost savings to the NHS as a result of its use. For instance, in the case of Charlie above, following advocacy intervention he was able to be discharged from hospital where he had been an inpatient needlessly for 9 months.</p>
74	Royal College of General Practitioners		The role of the dentist in referring non-healing ulcers rapidly for biopsy and assessment should be emphasised. (PS)
75	Royal College of General Practitioners		Early diagnosis and appropriate referral. Nil in the guidelines about this. With goitre and thyroid lumps being immensely common in primary care. Isolated lymphadenopathy also very common in young adults nearly always benign in nature guidance would help as the system cannot cope with any more work. (JS)
		No comments	
76	Association for Palliative Medicine		The quality standards that are under consideration are not relevant to palliative medicine and so, on this occasion, the APM won't be submitting a formal response
77	Department of Health		I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
78	NHS England		We can confirm that there are no comments to be made on behalf of NHS England.
79	Royal College of Nursing		Royal College of Nursing were invited to review the draft quality standard head and neck cancer. There are no further comments to make on this document on behalf of the Royal College of Nursing.

Registered stakeholders who submitted comments at consultation

- Association for Palliative Medicine
- British Association of Endocrine and Thyroid Surgeons (BAETS)
- British Association of Oral and Maxillofacial Surgeons (BAOMS)

- British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS)
- British Dietetic Association (BDA) – Oncology Sub-group
- British HIV Association (BHIVA)
- British Thyroid Foundation
- Cancer National Specialist Advisory Group
- Department of Health
- Faculty of General Dental Practice (UK)
- Guy's and St Thomas' NHS Foundation Trust - Guy's hospital head and neck MDT
- NHS England
- Norgine Pharmaceuticals Ltd
- Nutricia Advanced Medical Nutrition
- Older People's Advocacy Alliance (OPAAL) UK
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Physicians and Surgeons of Glasgow
- Royal College of Speech and language Therapists
- Royal College of Pathologists
- The Society and College of Radiographers.