NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Oesophago-gastric cancer

Date of quality standards advisory committee post-consultation meeting:
11 September 2018

2 Introduction

The draft quality standard for oesophago-gastric cancer was made available on the NICE website for a 4-week public consultation period between 10 July and 7 August 2018. 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 19 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 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 questions:

4. For draft quality statement 2: Is a timeframe of 1 week from requesting the scan to reporting on the results of F-18 FDG PET-CT reasonable?

5. Do you have an example from practice of implementing the NICE guideline(s) 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 General comments

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

- It was generally agreed that the quality standard covers key areas for quality improvement, with stakeholders commenting that the statements were reasonable in their current form.
- Stakeholders felt that statements 1, 2 and 3 in particular would improve quality.
- A concern was raised that the quality standard focuses on radical treatment alone, although only around a third of adults with oesophago-gastric cancer are suitable for this pathway.
- Stakeholders highlighted that generally, the statements were measurable in their current form.
- Stakeholders commented that the statements reflect current commissioning practice in some areas.

Consultation comments on data collection (question 2)

- There were no general comments on data sources. Comments were received for specific statements.

Consultation comments on resource impact (question 3)

- Stakeholders commented that in some areas resources are in place to support the statements being achieved.
- Stakeholders commented that statements 1 and 3 may lead to cost-savings.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults with oesophago-gastric cancer have their treatment reviewed by a multi-disciplinary team (MDT) that includes an oncologist and a specialist radiologist with an interest in oesophago-gastric cancer.

Consultation comments

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

- Statement
  - There was support for the statement, with stakeholders commenting specifically that it may support quality improvement.
  - Highlighting 2 roles means that the range of professionals involved in a multi-disciplinary team (MDT) treating adults with oesophago-gastric cancer is not reflected. The roles of dietitians and speech and language therapists were highlighted specifically.
  - The statement should focus on other aspects of MDT working. Streamlining of MDTs and development of protocols to avoid unnecessary repeat or multiple discussions was highlighted as a specific area.
  - Stakeholders suggested the radiologist could be described as a 'radiologist with a specialist interest in oesophago-gastric cancer'.
- Measures
  - Stakeholders suggested involvement of a clinical nurse specialist should be included as a measure of an MDT's quality, highlighting their contribution to positive outcomes such as life expectancy.
- Audience descriptors
  - Stakeholders suggested that the healthcare professionals descriptor should include a reference to other qualified professionals, because therapeutic radiographers attend MDTs in the place of oncologists in some centres.

Consultation comments on data collection (question 2)

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

- Some centres capture data electronically about MDT reviews, which is presented at local audits and at annual general meetings.

5.2 Draft statement 2

Adults with oesophageal or gastro-oesophageal junctional tumours (except T1a tumours) that are suitable for radical treatment have staging using 18 fluorodeoxyglucose positron emission tomography (F-18 FDG PET-CT).

Consultation comments

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

- General comments
  - There was support for this statement, with stakeholders highlighting specifically that the statement aligns with NHS England's timed oesophago-gastric cancer diagnostic pathway (currently in development, September 2018)
- This is a key area for quality improvement, highlighting:
  - PET-CT scanning is widespread in curative staging pathways.
  - Centres experiencing delays would benefit in particular.
- A concern was raised that the statement could be misinterpreted if it is read that PET-CT is the only staging test, highlighting that a sequence of tests should be first performed to detect obvious metastatic disease, which could avoid the need for a PET-CT scan.

Consultation comments on data collection (question 2)

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

- Local systems and structures are in place, with stakeholders commenting that MDTs at some centres record the planning and requesting of PET-CT scans as part of staging data.

Consultation question 4 (specific question for statement)

Is a time frame of 1 week from requesting the scan to reporting on the results of F-18 FDG PET-CT reasonable?

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

- There were mixed responses:
  - The proposed timescale was reasonable.
  - The timescale could be a challenge to achieve, highlighting access and reporting as potential barriers to delivery/implementation.
- Other urgent requests, from different services, would need to be considered when planning staffing and resources.
- Some local services may need additional investment.
- Some areas already aspire to a request-report timeframe of 7-10 days. One week should be regarded as the maximum time for referral to reporting, with reporting the next day being highlighted as best practice.

5.3 Draft statement 3

Adults with oesophago-gastric cancer have tailored specialist dietetic support before and after radical treatment.

Consultation comments

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

- General comments
  - There was support for the statement, with stakeholders commenting specifically that it may support quality improvement.
  - The statement should also cover delivering tailored specialist dietetic support during radical treatment.
  - All adults with oesophago-gastric cancer should have a nutritional assessment, which should be followed by support from specialist dietitians.
  - Stakeholders highlighted the importance of having specific roles in an MDT to deliver tailored, specialist dietetic support:
    - ◊ Dietitians; their provision of expert advice, treatment and support was commented on.
    - ◊ Speech and language therapists; their contribution to the assessment and management of dysphagia was commented on.
- Audience descriptors
  - A concern was raised that the wording may imply a one-to-one nutritional assessment could be replaced by a leaflet.
- Definitions
  - Stakeholders commented on the definition of the dietitian role, suggesting that a range of dietitian roles had the appropriate specialist knowledge and experience of both oesophago-gastric cancer and working in an MDT.
  - Stakeholders suggested including immunonutrition, the management of dysphagia, and support for adults with oesophago-gastric cancer who have an oesophageal stent in-situ.

- Stakeholders questioned the evidence that shows specialist oesophago-gastric cancer dietitians achieve better outcomes than a clinical nurse specialist/clinician, alongside input from a dietitian for tube/percutaneous endoscopic gastrostomy (PEG) feeding regimens.
- There was support for the areas identified, additional groups were suggested:
  - ◊ People with disability, severe mental illness.
  - ◊ Stakeholders also queried whether there are additional considerations associated with adults who are older.

Consultation comments on data sources (question 2)

- Stakeholders commented that some centres manually record whether dietetic support is required, and that who delivers it is registered in MDT attendance records.

Consultation comments on resource impact (question 3)

Stakeholders made the following comments in relation to consultation question 3:

- There was a mixed response to this question, with stakeholders commenting that specialised dietetic support is good in some areas.
- A concern was raised about capacity, specifically
  - Access to specialist oesophago-gastric dietitians could be difficult to achieve in all locations.
  - Numbers of WTE staff and workload would need reviewing.

5.4 Draft statement 4

Adults with oesophago-gastric cancer have access to an oesophago-gastric clinical nurse specialist.

Consultation comments

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

- General comments
  - There was some support for this statement.
- Quality measures / audience descriptors
  - Specific interventions delivered from diagnosis should be referenced to support measurability and understanding from the perspectives of adults with oesophago-gastric cancer, healthcare professionals, providers and commissioners. Health assessment to support delivery of the recovery package was highlighted as an example, along with assessment at diagnosis, and prior to starting treatment.
- Equality and diversity considerations
  - There was support for the areas identified, but additional groups were suggested:
    - ◊ People with disability, severe mental illness.
    - ◊ Stakeholders also queried whether there are additional considerations associated with adults who are older.

Consultation comments on data sources (question 2)

- Stakeholders commented that in some centres episodes of care involving a clinical nurse specialist are recorded.

Consultation comments on resource impact (question 3)

- Stakeholders commented that in some areas, sufficient numbers of clinical nurse specialists were available to support adults with oesophago-gastric cancer.
- The following concerns were raised:
  - Insufficient numbers of clinical nurse specialists at major centres.

- Variation in population need and workforce structure nationally.
- Lack of clarity regarding caseload and arrangements for cover.

6 Suggestions for additional statements

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

- A stand-alone statement on psychological support, with psychosocial support, information about cancer and sign-posting to peer support groups highlighted as specific areas.
- Diagnosis of oesophago-gastric cancer, highlighting diagnostic endoscopy specifically. Quality of gastroscopy/endoscopy, and access to endoscopy within a suggested timescale of within 7 days of referral were proposed as specific areas.
- Patient experience / quality of life through and beyond treatment, underpinned by recording patient-reported outcome measures (PROMS) and patient-reported experience measures (PREMS).
- Safety, underpinned by a measure relating to mortality within set intervals after having systemic anti-cancer therapy (SACT).
- Service quality, underpinned by a measure relating to the proportion of adults who had radiotherapy for the radical treatment of oesophageal cancer using intensity modulated radiotherapy (IMRT).
- Therapeutic endoscopy, with endoscopic resection for early neoplasia of the upper GI tract being highlighted specifically.
- Transfer and referral to a specialist MDT, proposing a timescale of within 14 days of referral.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
01	Department of Health and Social Care	No comment	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.
02	Merck Sharp & Dohme Ltd	No comment	Thank you for the invitation to participate in the oesophago-gastric cancer quality standard. We support the statements and suggestions made.
03	Royal College of Nursing	No comment	With regards to the above quality standard, I can advise that the RCN do not have any comments to submit on this occasion. We would however like to thank you for the opportunity to participate.
		General comments	
04	British Society of Gastrointestinal and Abdominal Radiology		BSGAR agrees the draft QS accurately reflects the key areas for quality improvement. A few additional points were raised as suggestions for further discussion and consideration [note: these are in the relevant section below]
05	Royal College of Physicians and Surgeons of Glasgow		The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow represents Fellows and Members throughout the United Kingdom who practice in the field of Oesophago-gastric cancer. While NICE has a remit for England, many of the recommendations are applicable to all devolved nations including Scotland. They should be considered by the relevant Ministers of the devolved governments. The College welcomes this review of Oesophago-Gastric Cancer by NICE. This is a disease which in the past has had a poor prognosis with miserable consequences for patients and their families. The College's expert reviewers welcome the Quality Standard and are in agreement with the recommendations proposed. One states that "The quality standards all seem entirely reasonable and appropriately measurable so think we can support them without any amendment."

[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]
06	The Royal College of Physicians, England		The document Quality Standard was rather limited in achieving its aspiration to reduce variation and improve quality of OG Cancer Services in the UK So whilst previous NICE service guidance has really shaped OG Cancer services in the UK it was felt that these would far less effect A few examples were given such that if one wanted to loom at safety, service quality or patient experience QoL: proposed measures could be deaths within 30/90 days of SACT, %use of IMRT for radical oesophageal RT and the recording of PROMs/PPREMs for oesophageal cancer patients through and beyond treatment. We did think it was a shame that that there was not a collaboration between this QS and the promotion of high quality research and participation in audit as it is felt that these are established service quality metrics in their own right.
07	NHS England – Specialised cancer surgery reference group		The quality standards focus on radical treatment. However, only a third of patients are suitable for radical treatment. Most patients either have locally advanced disease or metastasis. Quality standards for the management of these patients is lacking from the document and this should be considered.
08	NHS England – Specialised cancer surgery reference group		It is stated that this is quality standard is intended to cover diagnosis. There is no reference to diagnostics in the draft document. On page 17, it states it is expected to contribute to cancer staging, nutritional status, QoL and patient satisfaction – This should be expressed here
09	The Royal College of General Practitioners	Psychological and Rehabilitation	There is no quality statement on psychological support. People with oesophago-gastric cancer benefit from psychosocial support, verbal and written information about their cancer and care, and other sources of advice including peer groups
		Question 1	
10	British Society of Gastroenterology		*There are however certain standards which are essential for ensuring quality improvement and thus outcomes for OG cancers below:* 1. All patients referred with upper gastrointestinal symptoms under the suspected cancer pathway should have high quality gastroscopy as defined by the BSG. 2. All patients with early neoplasia of the upper GI tract should be considered for curative organ-sparing endoscopic resection as per BSG guidelines on Barretts oesophagus and European guidelines on endoscopic resection; this is much more important as the NOGCA shows each year that there is widespread and unwarranted variation in the number of patients with HGD/early ca undergoing endotherapy or instead “surveillance”. BSG would encourage NICE to incorporate quality standards on diagnostic and therapeutic endoscopy. *The Gastroduodenal section is also fully signed up to the final consensus view. It does not have anything fresh to*

ID	Stakeholder	Statement number	Comments[1]
			add at this stage, although it would certainly fully support and endorse the comments above, especially those about quality standards for endoscopy.
11	NHS England - Clinical Effectiveness		Standards around access time to endoscopy (e.g. within 7 days of referral) could drive quality improvement for the pathway In addition a quality standard around interprovider transfer / referral to specialist MDT (e.g. within 14 days of referral) could reduce unnecessary delays in care
12	Royal College of Speech and Language Therapists		Key areas are clearly identified however there may be potential quality control and cost savings particularly pertaining to the following quality standards […]. *See statements 1 and 3 – below.*
		Question 3	
13	NHS England – Clinical Effectiveness		Promoting quality of endoscopy would reduce false negatives / inadequate biopsies and improve efficiency of care (less repeat endoscopy) – currently around 10% for OG
	Statement 1		
14	Boston Scientific	Measures	NG83 states "Offer all people with oesophago-gastric cancer access to an oesophago-gastric clinical nurse specialist through the person's multidisciplinary team." We believe it would be a more accurate measure in quality if we include the oesophago-gastric clinical nurse specialist in the MDT as outline by NG83. The University of Nottingham reported in a new study looking at the picture of lung cancer care in England finds that patients with lung cancer experience significantly better outcomes in terms of life expectancy, avoiding unnecessary hospital admissions and managing the effects of treatment when cared for by specialist lung cancer nurses (https://www.nottingham.ac.uk/news/pressreleases/2018/july/care-provided-by-specialist-cancer-nurses-helps-improve-life-expectancy-of-patients-with-lung-cancer-says-new-study.aspx) A recent study reported at the European Lung Cancer Congress (ELCC 2018) -- Geneva, Switzerland -- April 11-14, 2018 "Better quality of life and cancer patients' satisfaction with a coordinating nurse. • Abstract 231P_PR 'Impact of the continuity of nursing care delivered by a pivot nurse in oncology on improving satisfaction and quality of life of patients with advanced lung cancer': presented by Elie Kassouf during the Poster Display session on Thursday, 12 April, 12:30 to 13:00 (CEST) in Hall 1. Journal of Thoracic Oncology, Volume 13, Issue 4, Supplement, April 2018 • Strutkowski, M, Saucier, A, Eades, M, Swidzinski, M, Ritchie, J, Marchionni, C, & Ladouceur, M (2008). Impact of a pivot nurse in oncology on patients with lung or breast cancer: Symptom distress, fatigue, quality of life, and use of healthcare resources. Oncology Nursing Forum, 35: 948-954 • Wagner, EH, Ludman, EJ, Aiello Bowles, EJ, Penfold, R, Reid, RJ, Rutter, CM et al. (2014). Nurse navigators in early cancer care: A randomized, controlled trial. Journal of Clinical Oncology, 32(1): 12-19

ID	Stakeholder	Statement number	Comments[1]
			• http://www.esmo.org/Conferences/ELCC-2018-Lung-Cancer http://www.iaslc.org/about-lung-cancer
15	British Society of Gastrointestinal and Abdominal Radiology	General comment	Radiologist with a specialist interest in oesophago-gastric cancer
16	British Society of Interventional Radiology	General comment	The MDT should include an endoscopist, pathologist, oncologist, radiologist, surgeon, palliative care specialist. In view that the majority of cases are diagnosed on endoscopic biopsy. Curative surgery and palliative care rates grossly vary regionally and having a truly multidisciplinary panel should reduce that regional fluctuations in care.
17	Macmillan Cancer Support	Rationale	This statement is not a clear representation of the health professional team required for managing the treatment (including prehabilitation and recovery) of this complex group of patients. The statement may therefore be disengaging to other health professionals/ does not outline the specific and vital roles of other health professionals within the MDT at point of diagnosis. Complex treatments should be planned in partnership with a full MDT including CNS + Allied Health professionals + Psychological support etc. This is also supported by the data supplied in comment number 3 below. Evidence: • Transforming Cancer Services Team for London (2018) The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer https://www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf • Macmillan Cancer Support (2006) Worried sick: the emotional impact of cancer https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf
18	NHS England – Clinical Effectiveness	General comment	Agree – aligns well with the proposals for national pathway. Also consider work on streamlining of MDT's and developments of protocols to avoid unnecessary repeat / multiple discussion – more detailed guidance due from NHSE in early 2019
19	NHS England – Specialised cancer surgery reference group	General comment	The first statement describes the MDT membership. It is recommended that the standard for MDT membership should use the same definition as included in Improving Outcomes Guidance; this includes surgeon, pathologist, medical and clinical oncologist, gastroenterologist / endoscopist.
20	NHS England – Specialised cancer surgery reference group	General comment	It is stated that this is quality standard is intended to cover diagnosis. There is no reference to diagnostics in the draft document. On page 17, it states it is expected to contribute to cancer staging, nutritional status, QoL and patient satisfaction – This should be expressed here
21	Oesophageal Patients Association	General comment	MDT must include specialised Dietician at all times, to ensure the dietary needs of each patient is known and addressed.

ID	Stakeholder	Statement number	Comments[1]
22	Royal College of Speech and Language Therapists	General comment	Key areas are clearly identified however there may be potential quality control and cost savings particularly pertaining to the following quality standards: QS 1 'Adults with oesophago-gastric cancer have their treatment reviewed by a multidisciplinary team (MDT) that includes an oncologist and a specialist radiologist with an interest in oesophago-gastric cancer.' QS 3 'Adults with oesophago-gastric cancer have tailored specialist dietetic support before and after radical treatment'. We would recommend both quality statements include enlisting of specialist Speech and Language Therapist support as part of the MDT review and in relation to 'dietetic support'. Major difficulties with nutrition following oesophago-gastric cancer (especially of upper- tract/ neck/ throat) arise from difficulties with swallowing, which a speech and language therapist must assess and manage. Recent evidence (Atrill et al., 2018) suggests that: '**dysphagia significantly increases healthcare utilisation and cost**' and that it is important to recognise that '**dysphagia as an important contributor** to pressure on healthcare systems.' Support for dysphagia before and after radical treatment by a Speech and Language Therapist would be a beneficial inclusion in the quality standard. Data can be as easily obtained as for other professionals listed.
23	The Society and College of Radiographers	[Audience descriptors]	Page 5: Healthcare professionals (oncologists and specialist radiologists with an interest in oesophago-gastric cancer) take part in MDT reviews to support decision-making and treatment planning Comment: It is made clear both at the start and throughout the document that patients should have their treatment reviewed by a MDT that includes an oncologist and specialist radiologist. An aspirational MDT is more than this and additional requirements laid out in the CRUK document https://www.cancerresearchuk.org/sites/default/files/executive_summary_meeting_patients_needs_improving_the_effectiveness_of_multidisciplinary_team_meetings.pdf The Society and College of Radiographers would request 'other qualified professional' be mentioned, as we are aware of consultant Therapeutic Radiographers attending MDTs instead of Oncologists for treatment sites.
		Question 1 – statement 1	

ID	Stakeholder	Statement number	Comments[1]
24	NHS England – Mid and South Essex Joint Commissioning Team		Yes, the draft quality standard reflects current practice in Mid and South Essex. Commissioners have in place joint working arrangements with specialised commissioning and Mid Essex Hospital Services NHS Trust including clinical protocols, network policies and referral criteria inclusive of inter-provider transfer
		Question 2 – statement 1	
25	NHS England – Mid and South Essex Joint Commissioning Team		Local systems and structures are in place to capture MDT review and planning for all patients who have been diagnosed with oesophago-gastric cancer. Data is recorded on a weekly basis by Mid Essex Hospitals NHS Trusts using the Somerset Cancer Register and is presented at Audit, and Annual General Meetings. Reviews within the actual MDT includes oncologists and interventional radiologist with interest in oesophago-gastric cancer.
		Question 3 – statement 1	
26	NHS England – Mid and South Essex Joint Commissioning Team		Locally as commissioners of the oesophago-gastric cancer service we are assured that current resources are in place to maintain a high quality service.
	Statement 2		
27	British Society of Gastroenterology	General comment	PET is very widespread in curative staging pathways; however there may be issues in other areas of the country with delays that mean this statement has value.
28	NHS England – Clinical Effectiveness	General comment	Agree and aligns well with proposed national pathway
29	NHS England – Specialised cancer surgery reference group	General comment	The second quality statement refers to the use of PET-CT. This section could be misinterpreted and could read as though PET-CT is the only staging test. The sequence of OGD and Biopsy, then CT for obvious mets must be emphasised and by doing this approach (OGD / CT), this obviates the need for PET in cases with clear metastatic disease.
30	Oesophageal Patients Association	General comment	All good and effective in identifying treatment required.
		Question 1 – statement 2	
31	NHS England – Mid and South Essex Joint Commissioning Team		Yes, The draft quality standard reflects current commissioning in place for patients with oesophageal or gastro-oesophageal junctional tumours in line with NICE NG83.
		Question 2 – statement 2	
32	NHS England – Mid and		Local systems and structures are currently in place to capture clinical staging at time of MDT review which

ID	Stakeholder	Statement number	Comments[1]
	South Essex Joint Commissioning Team		incorporates planning and requesting of PET-CT. The data is recorded on Somerset Cancer Register.
		Question 3 – statement 2	
33	NHS England – Mid and South Essex Joint Commissioning Team		Locally as commissioners we monitor the oesophago-gastric cancer service on a regular basis and are assured local systems and structures are in place for the current population number.
		Question 4 – statement 2	
34	British Society of and Gastrointestinal and Abdominal Radiology		3) A time frame of 1 week from request to report of PET CT may be challenging to achieve.
35	NHS England – Clinical effectiveness		Is reasonable timeframe but implementation / delivery will be challenging given issues in access to PET-CT imaging and reporting.
36	NHS England – Mid and South Essex Joint Commissioning Team		Oesophago-gastric PET service aspire to a turnaround time of between 7-10 days from request to reporting. From a commissioning perspective a 7 day rule from request to reporting sounds reasonable; however, this will have resource implications for staffing PET services and may require investment into local services.
37	The Society and College of Radiographers		Yes, provided adequate resources are provided to allow sufficient staffing and resources (radiographer/nuclear medicine technician/consultant radiologist/nuclear medicine physician) taking into account the other urgent demands that are made on services e.g. cancer, cardiac, acute and emergency imaging etc. The National Diagnostic Imaging Board (2008) have issued Radiology Reporting Times Best Practice Guidance stating that the aim is for reports to be available within 48 hours; therefore an aim for referral to report available at 1 week should be a maximum (with best practice aim for next day). The Society and College of Radiographers advocates that in order for the provision of a timely report to be achieved then routine use of adequately trained advanced clinical practice radiographers and nuclear medicine technicians (Masters level training, nuclear medicine reporting) must be the norm, with teamwork facilitated in partnership with consultant radiologist mentors.
	Statement 3		
38	Action against Heartburn	General comment	The statement about the importance of specialist dietetic support is absolutely supported as a very important issue for patients. Because of the length of the time that the treatment pathway can take, and as part of the tailoring of dietetic support to individual patients, there should be a minor, but important, amendment to clarify that the dietetic

ID	Stakeholder	Statement number	Comments[1]
			support will be important for some patients during the radical treatment. The statement should then read: *Statement 3: Adults with oesophago-gastric cancer have tailored specialist dietetic support before, during and after radical treatment.*
39	British Association of Parenteral and Enteral Nutrition	Dietetic support: what it means for healthcare professionals	In this section, as the text reads the standard could be met by providing a leaflet to patients rather than offering a one-to-one dietetic assessment. BAPEN feel that an in person assessment by a registered dietitian with experience of oesophago-gastric cancers should be standard practice and the standard should make it clear that this is necessary to meet the standard and that written material should offer a supporting role to supplement this one-to-one assessment.
40	British Dietetic Association – Oncology specialist group	General comment	We feel that this should target the whole treatment pathway and not just radical treatment. Many patients on all treatment pathways may have nutritional problems and can develop lower GI late effects. Nationally we are moving forward with late effects and living with and beyond of cancer and therefore we feel this needs to be encompassed into the quality standard.
41	British Dietetic Association – Oncology specialist group	General comment	We would recommend that this quality standard should read: Adults with oesophago-gastric cancer have tailored specialist dietetic support before and after radical treatment by a **specialist oncology dietitian**. The importance of having a specialist oncology dietitian is that they would be part of the patients' MDT and have specialist knowledge and experience within oesophago-gastric cancer. Their specialist knowledge may include; knowledge of treatments and managing their side effects and their attendance at specific training days related to UGI. There are many specialist oncology dietitians with experience or an interest in upper GI cancers who would be able to provide the expert advice, treatment and support required. They may not be called an UGI specialist in their job title but have this as part of their role. The following documents could be used as a link to support the level of dietetic expertise required: NICE Improving Supportive and Palliative Care for Adults with Cancer: https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005 Macmillan Allied Health Professions Competence Framework: https://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf
42	British Society of Gastroenterology	General comment	*Access to specialist oesophago-gastric cancer dietitians may be challenging in all locations, so this standard needs more work to be of any value.*
43	British Society of Gastrointestinal and Abdominal Radiology	General comment	1) Consider specifying that diatetic support include patients with swallowing difficulties or have an oesophageal stent in situ.

ID	Stakeholder	Statement number	Comments[1]
44	British Specialist Nutrition Association Ltd	Tailored specialist dietetic support (page 11)	Under 'Specialist dietetic support can include', we suggest the inclusion of the option for using immune nutrition as a tailored dietetic support for these patients pre- and post-surgery. A meta-analysis has shown positive results. Cerantola Y, Hubner M, Grass F et al (2011) Immunonutrition in gastrointestinal surgery British Journal of Surgery 98:37-48
45	Macmillan Cancer Support	Equality and diversity considerations	Considerations here are sound. We would like to see more considerations made from others with diverse backgrounds and from individual groups – those with disability, severe mental illness, are there any additional considerations for those who are obese, older adults etc. Evidence: • Macmillan Cancer Support (2017) Mind the Gap, Cancer Inequalities in London https://www.macmillan.org.uk/_images/4057%20MAC%20Report%202017_tcm9-319858.pdf • NHS England (2015) Equality and Health Inequalities Analysis: Refreshed NHS Continuing Healthcare Redress Guidance 2015 https://www.england.nhs.uk/wp-content/uploads/2015/04/equal-hlth-inequal-anlys.pdf
46	NHS England – Specialised cancer surgery reference group	General comment	It is recommended that this quality statement is enhanced/strengthened. All patients should have a nutritional assessment to determine their nutritional needs and then they should be supported by specialist dietitians. It is recommended that WTE and caseload are considered.
47	Oesophageal Patients Association	General comment	Specialised Dietetic support is good at most centres and Dietician needs to be part of the MDT from diagnosis, nutrition is important to enhance outcome of treatment and in quality of life during treatment.
48	Oesophageal Patients Association	General comment	The OPA have produced a video about nutrition and living with Oesophageal cancer, this is available as a DVD free to all patients or can be accessed at www.whatcanieatnow.co.uk This DVD is available for all healthcare centres free of charge for distribution to patients once staged for surgery and may be helpful for Healthcare specialists as well as patients in ensuring nutrition is at the forefront from diagnosis and as a backup tool which can be accessed away from a clinical setting.
49	Oesophageal Patients Association	General comment	Fitness as well as nutrition will also aid better outcomes and aid tolerance of treatment, fitness is not addressed in this draft but should be considered by each treatment centre.
50	Royal College of Speech and Language Therapists	General comment	Key areas are clearly identified however there may be potential quality control and cost savings particularly pertaining to the following quality standards: QS 1 'Adults with oesophago-gastric cancer have their treatment reviewed by a multidisciplinary team (MDT) that

ID	Stakeholder	Statement number	Comments[1]
			includes an oncologist and a specialist radiologist with an interest in oesophago-gastric cancer.' QS 3 'Adults with oesophago-gastric cancer have tailored specialist dietetic support before and after radical treatment'. We would recommend both quality statements include enlisting of specialist Speech and Language Therapist support as part of the MDT review and in relation to 'dietetic support'. Major difficulties with nutrition following oesophago-gastric cancer (especially of upper- tract/ neck/ throat) arise from difficulties with swallowing, which a speech and language therapist must assess and manage. Recent evidence (Atrill et al., 2018) suggests that: '**dysphagia significantly increases healthcare utilisation and cost**' and that it is important to recognise that '**dysphagia as an important contributor** to pressure on healthcare systems.' Support for dysphagia before and after radical treatment by a Speech and Language Therapist would be a beneficial inclusion in the quality standard. Data can be as easily obtained as for other professionals listed.
		Question 1 – statement 3	
51	NHS England – Mid and South Essex Joint Commissioning Team		Yes, The draft quality standard reflects current commissioning in place for patients with oesophago-gastric cancer in line with NICE NG83.
		Question 2 – statement 3	
52	NHS England – Mid and South Essex Joint Commissioning Team		Local systems are in place to record manually dietetic support required. As part of the UGI MDT attendance record, dietetic nurse specialists are registered at meetings.
		Question 3 – statement 3	
53	NHS England – Mid and South Essex Joint Commissioning Team		Locally as commissioners we monitor the oesophago-gastric cancer service on a regular basis and are assured local systems and structures are in place for the current population number in accordance with NG83.
	Statement 4		
54	British Society of Gastroenterology	General comment	*There is no evidence as far as I am aware that there are better outcomes from seeing an OG cancer specialist dietician as opposed to having nutritional needs addressed by a CNS/ clinician, with general dietician help for tube/PEG feeding regimen.*
55	British Society of	General	Consider specifying patients need access and input from clinical nurse specialist.

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	Gastrointestinal and Abdominal Radiology	comment	
56	Macmillan Cancer Support	("Quality statement and contents")	Macmillan's recent cancer workforce in England census showed that the relationship between the numbers of cancer patients and the size of the specialist cancer nursing workforce is variable. The report states: *this variation needs to be put into the context of the varying levels of need and variation in workforce structure. Therefore, this document does not represent guidance on appropriate caseload or, indeed, the total number of specialist adult cancer nurses required. It merely acknowledges variation in the provision of these posts across different areas of practice with a view to stimulating further discussion and exploration of circumstances and local arrangements.* We would therefore ask that further exploration is put into this statement and whether there is more context that could be given to the statement around access to a CNS. Evidence: Macmillan Cancer support (2018) *Cancer workforce in England* https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotheraphy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf
57	Macmillan Cancer Support	*(What the statement means for different audiences)*	This statement refers to what this quality standard means for different audiences. We would suggest including explicit use of the recovery package and other interventions relating to the care of patients from the point of diagnosis through to recovery/end of life interventions within this statement to provide more measurability to the statement. As an example inclusion specifically of mention of a health needs assessment has meaning and value for each of the different audiences mentioned: - For service providers it allows opportunity to collect data that can help shape what services should look like and help with commissioning conversations - Health professionals are provided knowledge of the needs of this patient population which directly influences ability to care including identification of possible side effects including long term and late effects and practical and psychological support required - For commissioners they are provided with a greater understanding of the needs of this patient population and evidence of what services should be commissioned. - For service users: knowledge that their needs are being addressed and that thought has been put into common needs of this patient population and that services have been developed in response to these. As an example of how this data can be used we looked at the Macmillan electronic Holistic Needs Assessment data we have available and the top concerns identified from these assessments. For the two years 1/7/2016 to 30/6/2018

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			there were 781 assessments/704 unique individuals. From that data it was identified that the top 20 concerns in that two year period were: Eating, appetite or taste 438 Tired, exhausted or fatigued 385 Changes in weight 318 Worry, fear or anxiety 273 Pain or discomfort 226 I have questions about my diagnosis, treatments or effects 220 Constipation 185 Moving around (walking) 183 Indigestion 182 Sleep problems 177 Nausea or vomiting 167 Anger or frustration 159 Swallowing 156 Sadness or depression 154 Breathing difficulties 150 Partner 150 Sore or dry mouth, or ulcers 137 Memory or concentration 123 Thinking about the future 111 Dry, itchy or sore skin 109
58	Macmillan Cancer Support		Another example is the CREW longitudinal study whilst initially on 1000 colorectal cancer patients with widening to other cancer types; and with transferable insight to other cancer types. Eligible patients were approached in 29 UK hospitals prior to their surgery and invited to participate. Participants completed questionnaires pre-surgery and at regular intervals up to 5 years later. Clinical data were also collected regarding tumour type, treatment, recurrence etc. Summary of key recommendations: • Early assessment (soon after diagnosis) of confidence to manage illness related problems and depression to identify those most at risk of poorer recovery experiences in terms of health and well-being. In CREW this accounted for 30% of the cohort. • Targeted interventions to support those identified as lacking confidence to manage (around 30% of patients with treated with curative intent) • Improved access to appropriate support for those reporting clinical levels of depression (21% reported clinical

ID	Stakeholder	Statement number	Comments[1]
			levels of depression before surgery) • Regular assessments of confidence to manage, depression, social support, nature of co-morbidities and whether they are limiting daily life soon after treatment and into follow-up to inform appropriate intervention/signposting/referral to specialist services as appropriate These recommendations are informed by published papers to date and listed below. 1. Recovery of health and wellbeing following surgery • Most people (70%) recover well after treatment for colorectal cancer in terms of their health and well-being • Around 30% have poorer psychosocial outcomes up to two years later. • Those with low confidence to manage illness related problems and depression pre-surgery are most likely to have poorest outcomes. Recommendations: Early assessment of confidence to manage and depression (soon after diagnosis) to identify those most likely to need support in their recovery. Evidence: Foster, C., J. Haviland, J. Winter, C. Grimmett, K. Chivers Seymour, L. Batehup, L. Calman, J. Corner, A. Din, D. Fenlon, C. M. May, A. Richardson, P. W. Smith and C. Members of the Study Advisory (2016). ""Pre-Surgery Depression and Confidence to Manage Problems Predict Recovery Trajectories of Health and Wellbeing in the First Two Years following Colorectal Cancer: Results from the CREW Cohort Study."" PLoS One 11(5): e0155434. http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0155434
59	Macmillan Cancer Support	Equality and Diversity Considerations	Considerations here are sound. We would like to see more considerations made from others with diverse backgrounds and from individual groups – those with disability, severe mental illness, are there any additional considerations for those who are obese, older adults etc. Evidence: • Macmillan Cancer Support (2017) Mind the Gap, Cancer Inequalities in London https://www.macmillan.org.uk/_images/4057%20MAC%20Report%202017_tcm9-319858.pdf • NHS England (2015) Equality and Health Inequalities Analysis: Refreshed NHS Continuing Healthcare Redress Guidance 2015 https://www.england.nhs.uk/wp-content/uploads/2015/04/equal-hlth-inequal-anlys.pdf
60	Oesophageal Patients Association	General comment	I do feel that patient support by other patients is important in helping those put forward for radical treatment as can offer non clinical advice on adapting changes to life after surgery, this is a backup to the CNS role only as patients can ask questions that they feel are unable to ask clinical professionals. I would suggest that all patients are given details of their local support group once surgery is planned, this can be a simple contact flyer with contact details if they so want to make contact. Control and agreed guidelines are important, we at the OPA ensure all group coordinators are trained and have full support from our Head Office and patient trustees.

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61	Oesophageal Patients Association	General comment	CNS's are very important as normally the main contact with patients, especially during treatment but are often overwhelmed with the amount of patients diagnosed in major centres. Cover needs to be considered carefully dependant on the flow of each centre.
62	Royal College of General Practitioners	General comment	Clinical nurse specialist. There has been an expansion in the numbers of nurse specialists in numerous fields, at a time when there are big shortages of nurses in other posts. There are concerns that specialist nurses have in many cases become vertical programmes, cutting across generalist primary care. Is it known that the work done by nurses specialising in oesophago-gastric cancer could not equally well be done by a combination of care co-ordinators, rehabilitation programme, leaflets and GPs or practice nurses? Even if there were robust evidence that specialist nurses do it better, vertical programmes can be damaging to integrated care, and that using overall outcome measures (as opposed to disease-specific ones) investment in generalist primary care produces better outcomes than specialist care every time.
		Question 1 – statement 4	
63	NHS England – Mid and South Essex Joint Commissioning Team		Yes, The draft quality standard reflects current commissioning in place for patients with oesophago-gastric cancer in line with NICE NG83.
		Question 2 – statement 4	
64	NHS England – Mid and South Essex Joint Commissioning Team		Local systems and structures are in place to capture clinical nurse specialist's patient engagement episodes. The data is recorded on Somerset Cancer Register.
		Question 3 – statement 4	
65	NHS England – Mid and South Essex Joint Commissioning Team		Locally as commissioners we ensure that we commission services that provide enough clinical nurse specialists to support all adults with oesophago-gastric cancer. (M&S)

Registered stakeholders who submitted comments at consultation

- Action Against Heartburn (AAH)
- Boston Scientific (BS)
- British Association of Parenteral and Enteral Nutrition (BAPEN)
- British Dietetic Association (BDA) - Oncology specialist group
- British Society of Gastroenterology (BSG)
- British Society of Gastrointestinal and Abdominal Radiology (BSGAR)
- British Society of Interventional Radiology (BSIR)
- British Specialist Nutrition Association (BSNA) Ltd
- Department of Health and Social Care (DHSC)
- Macmillan Cancer Support (MCS)
- Merck Sharp & Dohme Limited (MSD)
- NHS England (NHSE) – 3 divisions:
  - Clinical Effectiveness
  - Mid and South Essex Joint Commissioning Team
  - Specialised cancer surgery reference group
- Oesophageal Patients Association (OPA)
- Royal College of Nursing (RCN)
- Royal College of Physicians and Surgeons of Glasgow (RCPSG)
- Royal College of Speech and Language Therapists (RCSLT)

- The Royal College of General Practitioners (RCGP)
- The Royal College of Physicians (RCP)
- The Society and College of Radiographers (RSCR)