

**NATIONAL INSTITUTE FOR HEALTH AND  
CARE EXCELLENCE**

**HEALTH AND SOCIAL CARE DIRECTORATE**

**QUALITY STANDARD CONSULTATION**

**SUMMARY REPORT**

**1 Quality standard title**

Suspected Cancer

Date of Quality Standards Advisory Committee post-consultation meeting:  
3<sup>rd</sup> March 2016.

**2 Introduction**

The draft quality standard for suspected cancer was made available on the NICE website for a 4-week public consultation period between 13<sup>th</sup> February and 10<sup>th</sup> March 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 37 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. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?
3. 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.

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

4. There are variations in referral rates for suspected cancer between general practices. Can you suggest which specific groups are not being referred appropriately in order to help define a specific population on which a quality statement can be written?

## **4 General comments**

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

- some stakeholders comment that important and topical issues related to suspected cancer referrals are addressed in the quality standard, and others felt that key areas are not covered
- The quality standard is feasible and reflects the key areas for improvement
- Families and carers must be involved in providing support to patients with suspected cancer
- Concerns were raised about whether primary care is the main route into diagnosis
- Concerns over absence of statements relating to children and young adults
- Concerns over the scope of the quality standard
- Key outcome measure should be about long-term survival rates

### **Consultation comments on data collection**

- Comments highlight that it should be relatively easy to collect the data for this quality standard if correctly and consistently completed
- National datasets and systems which could be used to evaluate the quality measures include:
  - Diagnostic waiting times
  - Cancer analysis system, including the Diagnostic Imaging Data set (DID), Hospital Episode Statistics (HES) and Public Health England's route to diagnosis analysis
- National cancer audits show variance in data collection across the country
- Concerns that data collection for statement 3 may be more difficult

## **5 Summary of consultation feedback by draft statement**

### **5.1 Draft statement 1**

People presenting in primary care with symptoms that suggest oesophageal or stomach cancer are offered an urgent direct access upper gastrointestinal endoscopy within 2 weeks.

#### **Consultation comments**

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

- Stakeholders support the inclusion of the statement
- Concerns over including 'direct access' in statement wording. Many Trusts offer 'straight to test' endoscopy within 2 weeks which has the same outcome as direct access
- Direct access may be a less safe mechanism and may introduce delays further down the pathway
- Suggestions to remove 'direct access' from statement
- Measuring direct access to GI endoscopy with 2 weeks may be superseded by the new 28 day faster diagnosis standard, in which diagnosis will be required within 4 weeks
- Inclusion of this statement will increase referrals for endoscopy
- Concerns about data collection, in particular difficulty in collecting denominator data for statement this statement
- Measuring the denominator would be possible but not straight forward
- Measuring the numerator would be possible using cancer waiting times in combination with the diagnostic waiting times (DM01)

### **5.2 Draft statement 2**

Adults presenting in primary care with symptoms that suggest colorectal cancer who do not have visible rectal bleeding, have a test for occult blood in faeces.

### **Consultation comments**

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

- Stakeholders welcome the inclusion of this statement and comment that the statement will increase referrals for endoscopy
- Stakeholders comment that this statement is controversial and is not the highest priority
- Concerns over the sensitivity and specificity of the faecal occult blood test (FOBT) and stakeholders suggest the use of the Faecal Immunochemical Test (FIT)
- Stakeholders propose delaying the inclusion of this statement until the NICE Diagnostics Advisory Committee assess and addresses unresolved issues relating to FIT use in primary care (publication date: April 2017)
- Stakeholders comment that this statement does not specify the use of FIT and this could cause ambiguity and confusion in commissioning any provision of testing for occult blood in faeces.
- To be reflective of a key area of quality improvement, this statement would need to be written in a more specific way to ensure people who require a more urgent referral are not delayed
- Concerns over collecting denominator data

### **5.3 *Draft statement 3***

People with suspected cancer who are referred to a specialist cancer service are given information to encourage them to attend their appointment.

### **Consultation comments**

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

- Stakeholders support the inclusion of quality statement 3
- Statement will help patients make informed decisions about care and will decrease patient initiated delays
- Information that is provided needs to be carefully balanced to avoid unnecessary anxiety

- Statement needs to be altered to include information for carers of young children
- Information should be provided in an age-appropriate manner and tailored to the patients level of understanding
- Stakeholders signpost a NHS leaflet entitled 'patient information for urgent referrals' and to a leaflet developed by Cancer Research UK entitled 'your Urgent Referral Explained' to support statement 3
- The statement could be reworded as some people with suspected cancer will be referred to a diagnostic test and not a specialist cancer service
- Concerns that the outcome will be difficult to measure
- Concerns that providing information prior to diagnosis will raise anxiety levels among patients and family members
- Concerns that statement 3 suggests that the responsibility for patients moving along the cancer care pathway lies with cancer patients

## **6 Suggestions for additional statements**

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

### **Consultation comments for question 4**

There are variations in referral rates for suspected cancer between general practices. Can you suggest which specific groups are not being referred appropriately in order to help define a specific population on which a quality statement can be written?

- Stakeholders commented that variation in referral rates are inevitable
- People with mental health problems and learning difficulties have poorer access to healthcare
- Men are less likely to attend primary care and more likely to visit pharmacies or chemists. Awareness of cancer among men needs to be increased to encourage health seeking behaviour
- Men need additional support in deciding whether to have a PSA test

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- Younger women with blood in their urine often have a delay in diagnosis as blood in urine is attributed to UTI
- There is wide variation between cancer types in people who had visited their GP 3 or more times before a hospital referral, these cancer types include:
  - Patients who have subsequent diagnosis of multiple myeloma, pancreatic, stomach or lung cancer
  - Younger patients (16-24 years)
  - People from ethnic minority groups
- Teenagers and young adults with cancer are less likely to present at their GP practice and have a high rate of emergency presentation
- Teenagers and young people are less likely to recognise common signs of cancer than older adults and late diagnosis is likely to impact disease progression and treatment
- Ethnic/religious groups may be less willing for a referral and some cultural groups are less likely to attend if the word 'cancer' is mentioned

### **General comments**

- Stakeholders suggest that more needs to be done to raise awareness of rarer cancers to increase the speed, effectiveness and accuracy of referrals
- Prioritisation of data collection for rarer cancer
- Fast and accurate referral is required to identify brain cancer and to maximise survival
- Stakeholders comment that there is value in a statement that recognises the need for primary care to be aware of NICE guideline NG12
- Lung cancer hasn't been specified given the prevalence and high mortality
- Stakeholders comment that quality statement development should be considered for:
  - Growing diagnostic capacity
  - GP access to secondary care expertise
  - Application of guidelines
  - Timeliness of investigation and reporting
  - Ensuring universal direct access to key investigative tests for suspected cancer

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## Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Comment on	Comments
11	The Brain Tumour Charity	General	<p>We do not believe that this draft quality standard accurately reflects the key areas for quality improvement and does not address the issues we raised in the engagement exercise that affect people with a brain tumour.</p> <p>The Brain Tumour Charity suggested three areas for quality improvement in the initial engagement exercise and we are disappointed that there are no measures in the draft quality standard for suspected cancer that will address the late diagnosis of paediatric brain tumours.</p> <p>The symptoms of a brain tumour are diverse and in isolation can often indicate/mimic other conditions. Due to the use solely of positive predictive value (PPV) to determine which symptoms should be included in the Guidelines on Suspected cancer: recognition and referral we are concerned about the absence of specific symptom recommendations for brain and CNS cancer such as those featured in the predecessor to this guideline, CG027.</p> <p>The HeadSmart Campaign, a joint initiative of The Brain Tumour Charity and the Children’s Brain Tumour Research Centre at the University of Nottingham, is backed by The Brain Pathways Guideline (The brain pathways guideline: a guideline to assist healthcare professionals in the assessment of children who may have a brain tumour) which has received NICE accreditation (1). Since the launch of HeadSmart the median Total Diagnostic Interval (TDI) (from appearance of first symptoms to diagnosis) for childhood brain tumours in the UK, as measured through the HeadSmart campaign, has reduced from 9 weeks in 2011 to 6.7 weeks in 2013.</p> <p>The NICE accreditation of the guideline on which HeadSmart is based means that there are two sources of contradictory guidance available to clinicians for the referral of a suspected paediatric brain tumour. We are disappointed that neither the Guidelines on Suspected cancer: recognition and referral nor this draft Quality Standard on Suspected Cancer have addressed the contradictory guidance available to clinicians. The inclusion of HeadSmart in the Guidelines on Suspected cancer: recognition and referral would have gone some way to addressing the availability of contradictory guidance.</p>

20	NHS England		Overall, we find these quality statements disappointing and a potentially wasted opportunity. We are not clear that these three statements represent the key areas for quality improvement. Whilst statements 1 and 3 are useful, it is unclear that statement 2 should be treated as a priority. In addition, as the introduction states, there are a large number of cancers, and it could be seen as excessively selective to reduce the quality statements on suspected cancer in general to two very specific statements about specific types of cancer. We appreciate that the purpose of the quality standard is not to be a comprehensive guide to good practice.
20	NHS England	General	The title and content of this quality standard is misleading. There are three standards which primarily relate only to upper and lower GI cancers. These are not unreasonable but this is not a generic cancer quality standard.
21	RCOG	General	<p>Many thanks for inviting the RCOG Guidelines Committee to review this document. The document addresses an important and topical issue related to quality standards covering recognition and referral of suspected cancer in children, young people and adults.</p> <p>The document is well written, and overall raised no major comments from the guideline committee members. It was felt that the quality standards were entirely reasonable and reflect key areas for improvement. It was also felt that it would be easy to collect the data for the proposed procedures. The only concern was collecting data regarding Statement 3 – Diversity, Equality and language “People with suspected cancer who are referred to a specialist cancer service are given information to encourage them to attend their appointment”. It was felt that it would be difficult to collect data about this statement, albeit a laudable and important one.</p> <p>Despite being titled “Suspected Cancer”, it was felt that this document only addressed the gastrointestinal cancers (oesophageal, stomach and colorectal), and the committee membership wondered whether this should be reflected in the title.</p> <p>Two typos were identified, and we trust that the document will be proof-read prior to its publication. The first was adding “to” after “encourage them” in statement 3 – Quality measures, to read: ‘Giving people information will reassure and encourage them to attend their appointment and reassure any doubts they may be having’.</p> <p>The second was to use the plural form in statement 3 – Definition of terms used in this QS, to read ‘Alternative diagnoses’.</p> <p>The last comment was pertinent to QUES 4, regarding variations in referral rates. An unanswered question could be whether the variations in referral rates could reflect over-referral in some practices (ie are some GP practices referring too many women with suspected cancer unnecessarily – leading to increased anxiety for the patients and workload for the referral centres) or under-referral by others (ie are some practices missing cases of cancer that should have been referred). The correct balance needs to be found.</p> <p>Finally, the committee would like to thank the NICE committee for asking us to comment on the document and for all the work and effort put in preparing it.</p>
23	Department of health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation

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25	British Medical Association	General	The primary concern of doctors is that services should be safe and patients should have positive experiences. To achieve this, services must be properly coordinated, and individual healthcare workers should be properly trained. Crucially, families and carers must be involved (where the patient wants this) in providing support to patients with suspected cancer.
27	Brain Tumour Research	Question 1	<p>The draft quality standard does make reference to crucial areas of the referral pathway, but it should also include a focus on rarer cancers.</p> <p>The draft quality standard correctly states that Domain 1 of the NHS Outcomes Framework 2015-16 prioritises incentivising treatments which reduce years of life lost. 71% of all brain tumour deaths occur in those under 75, compared to 47% for all cancers. Furthermore, brain tumours kill more children and adults under 40 than any other cancer. It is crucial, therefore, that suspected cancer quality standards make effective recommendations around education, identification and referral of rarer cancers, such as brain tumours, in particular in primary and community care settings where early diagnosis is more likely.</p>
28	Sandwell and West Birmingham CCG	Question 2	Only possible to collect the data if correctly and consistently completed, costed and submitted to common systems/structures as in the lung cancer audit. National cancer audits show variance across the country so it is very important to drill down into this to find out why and if this was compared with locally gathered data either by commissioners or providers, this could be contrasted to identify gaps/differences.
29	RCGP		Theoretically this quality standard does reflect a key area for quality improvement. (RM)
30	NCRI-RCP-ACP	General	<p>The NCRI/RCP/ACP are grateful for the opportunity to respond to the above consultation. We wish to make the following comments with regard to supportive and palliative care.</p> <p>The RCP also wishes to endorse the responses submitted by the British Thoracic Society (BTS), the Association of British Neurologists (ABN), and British Society of Gastroenterology (BSG). Please note that Dr Andrew Goddard, RCP registrar is also a member of the BSG Clinical Standards and Services Committee which helped compile the BSG response.</p>
32	Department of Health	Page 1: Why is this quality standard needed	What is the source of 'approximately one-third of the population will develop cancer'?
32	Department of Health	Page 1: Why is this quality standard needed	Is primary care really the main route into diagnosis? According to analysis by PHE analysis there are various routes to diagnosis including primary care. <a href="http://www.ncin.org.uk/publications/routes_to_diagnosis">http://www.ncin.org.uk/publications/routes_to_diagnosis</a> We propose that this reads 'Identifying people with suspected cancer can happen in primary care because .....

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32	Department of Health	Page 1: Why is this quality standard needed	The stuff on the indicators is quite confusing – e.g. don't understand why some of the GP experience stuff is relevant. To keep this simple, we think the document should refer to the NHS Mandate published on 17 December 2015 at <a href="https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017">https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017</a> and Public Health Outcomes Framework for England, 2013-16
32	Department of Health	Page 5 – Question 1	We are not sure that the current statements accurately reflect the key areas for quality improvement
32	Department of Health	Page 5 – Question 2	We believe so
32	Department of Health		As above in relation to Question1 - the statements only currently cover a number of tumour sites (none for children and young adults) with no clear rationale as to why these specific sites
34	British Association of Dermatologists	General	It is unclear why the standard predominantly addresses gastrointestinal cancers.
34	British Association of Dermatologists	Scope	We don't think the scope of the quality statements is sufficiently fundamental. We would have interest in creating an online electronic referral system populating a database of submissions and assisted with intelligent algorithms for referrers. This process should be able to take attachments including images and other data to enable the assessment and processing of the submission. The outcomes of the referrals should be an output of the electronic process and linked such that analysis of the submission can be done with respect to features on presentation, demographic, referring source and other pathology specific criteria. Skin cancer would be a relatively easy example to start with.

<p>36</p>	<p>MDS UK Patient Support Group</p>	<p>Q1: The draft quality standards document does not accurately reflect the key areas for quality improvement. Considering that the three quality standards are derived from NG12 Guideline on the recognition and referral of suspected cancers, it is difficult to understand as to why the statements 1 and 2 refer specifically to two cancer sites.</p> <p>The quality standards should be about the overall improvements in the</p> <ol style="list-style-type: none"> <li>1) symptom suspicion and recognition,</li> <li>2) early referral and</li> <li>3) timely treatment of all cancers - and not only the cancers affecting the sites as referred to in the statements 1 and 2.</li> </ol> <p>The key element that is missing in the quality standards consultation document is reference to the timely treatment. For this reason, it is hard to imagine that the proposed quality standards will contribute to the improvements outlined in the NHS and Public Health Outcomes Frameworks as suggested in both, briefing and consultation documents for suspected cancers.</p> <p>Q2: The measurements for the quality statements as currently proposed may lead to only partial improvement of the overall care for cancer patients. The key measure that should be put in place is around the long-term survival rates for cancer patients as a result of the implementation of key standards: 1) symptom suspicion and recognition, 2) early referral and 3) timely treatment.</p> <p>Q4: Currently proposed standards 1 and 2 exclude all other cancer sites. In addition, the specific cancer population diagnosed with Myelodysplastic Syndrome has been completely unrecognised and left out of the original NG12 guidelines. Persistent anaemia must be recognised as a potential suspected blood cancer, as well as repeated infections, and/or repeated abnormal blood counts (RBC/WBC/Platelets). Currently still too many MDS patients are subjected to repeat gastroenterological investigations for suspected internal bleeding. Insufficient attention is given to repeat abnormal blood counts, especially when only one type of blood lines are affected. This leads to patients remaining undiagnosed for months, sometimes years, until the disease progresses. It would be crucial to update the NG12 list of symptoms – which is currently extremely limited and not representative of a large number of cancers – blood cancers especially. MDS can be a very fast progressing type of blood cancer, leading to chronic reliance on blood transfusions (RBC and/or platelets), frequent infections requiring hospital treatment – and ultimately sometimes progression to Acute Myeloid Leukaemia (AML) in about 30% of cases. This can be prevented/delayed with the relevant treatment, restoring patient’s quality of life and potentially their return to work for some of them.</p>
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37	Cancer Research UK	If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?	<p><b>1.</b> The Quality Standard suggests that 'local data collection' should be used to measure the impact of each quality statement. Uniform measurement of local data collection is unlikely and there would be insufficient mechanisms to ensure transparency and accountability. Without ensuring that the Quality Standards are measurable they will have little impact.</p> <p>It may be more useful to focus on a clear evaluation of the implementation of the NICE guidelines in a local area, to assess their impact and ensure they are deliverable, as set out in the cancer strategy.<sup>1</sup></p> <p>However, if these quality measures are adopted, it would be more beneficial to use existing data collection and analysis systems to evaluate the proposed quality measures as this will facilitate consistency and not duplicate existing analysis. National datasets and systems which could be used include:</p> <ul style="list-style-type: none"> <li>• Diagnostic Waiting Times (DM01)</li> <li>• Cancer analysis system: including the Diagnostic Imaging Data set (DID), Hospital Episode Statistics (HES) and Public Health England's Routes to Diagnosis analysis</li> <li>• Cancer Waiting Times</li> </ul> <p>For more detail on suggested measures for the proposed quality statements, please see the appendix.</p>
26	Bowel Cancer UK	Introduction	<p>Bowel Cancer UK welcomes the development of the Quality Standard (QS) on the recognition and referral of suspected cancer and supports the purpose of the QS to drive measurable improvements in cancer care. In particular, we support the three outcomes of 'time to diagnosis,' 'cancer-related morbidity,' and 'cancer mortality' that the QS should contribute to. Bowel cancer remains a significant health problem in the UK. It is the fourth most common cancer, with nearly 42,000 people diagnosed with bowel cancer every year and it is the second biggest cause of cancer related mortality in the UK, with 16,200 people dying from it. This is despite bowel cancer being preventable, treatable and curable. We welcome and support measures that can help towards achieving earlier diagnosis, as this has significant impact on survival rates for bowel cancer. Nine out of 10 patients survive bowel cancer were diagnosed in the earliest stage of the disease, compared to just one in 10 for those diagnosed in the latest stage.</p>

<sup>1</sup> Achieving World Class Cancer Outcomes: a Strategy for England, 2015 – 2020 (2015) Independent Cancer Taskforce

37	Cancer Research UK		<p>‘Evidence of local urgent direct access pathways’ could be evaluated through a combination of measuring the diagnostic waiting times dataset (DM01) and cancer waiting times. If you assume no change in patients presenting, to measure the impact of this quality standard, you could look at increased number of referrals. However, it should be noted that assuming ‘no change’ is a fairly weak assumption due to the potential impact of symptom awareness or incidence.</p> <p>To measure the proportion of people presenting with symptoms that suggest oesophageal or stomach cancer who have a referral for an urgent direct access upper gastrointestinal endoscopy, we suggest that instead of ‘local data collection’, it would be more realistic to measure ‘of those referred, how many were direct access’.</p> <p>Alternatively, the suggested denominator (number of people presenting in primary care with symptoms that suggest oesophageal or stomach cancer) could be collected in principle but this is not straight forward. Similar figures have been extracted for Be Clear on Cancer (BCOC) evaluations based on read codes. They would need to be linked to the General Practice Extraction Service (GPES)<sup>2</sup>. Although GPES can only collect coded data, precedent has been set as read codes were used for the BCOC evaluation. If a working primary care data collection system was successfully established, this may also be another source of similar data in future.</p> <p>Finally, to measure the proportion of people with symptoms that suggest oesophageal or stomach cancer who have an urgent direct access upper gastrointestinal endoscopy within 2 weeks of referral, this would be possible using cancer waiting times in combination with the diagnostic waiting times (DMO1).</p>
25	British Medical Association	Question 2	<p>Data collection on quantitative measures, such as the number of endoscopy referrals, is straightforward. Other quantitative measures, such as the number of patients not referred regarding suspicious symptoms, would be more challenging. Quality cannot be measured only with quantitative indicators – although qualitative outcomes are more difficult to measure (for example, patient experience) – they are crucially important measures and should not be overlooked. Patient experience questionnaires would be a useful starting point, but should not be the only measure</p>

<sup>2</sup> See <http://www.hscic.gov.uk/gpes>

24	Association of British Neurologists	Question 1	<p>Does this draft quality standard accurately reflect the key areas for quality improvement?</p> <p>This NICE guideline was specified to address recommendations relevant to all people with suspected cancer (though some that are specific to the site of the suspected cancer could also be included.) The first 2 statements are dedicated to two site-specific cancers. This information is currently included in current NICE guidelines, suspected cancer: recognition and referral (2015) NICE guideline NG12. It is not clear why these two statements are included in this current NICE quality standard. A more general statement on the importance of primary care access to appropriate investigations, which should be available to all and not dependent on locality, to improve time to diagnosis, may be more warranted.</p> <p>Statement 3 is relevant to all patients suspected with cancer with suggested advice on what information to provide.</p>
15	Royal College of Paediatrics and Child Health	Not present	<p>We feel it is disappointing that the suggestion for children and young people’s experience of multiple GP visits before suspicion of cancer (and referral) is made, and an attempt to reduce this, is not a quality standard.</p> <p>This applies particularly in the area of sarcoma, in which it appears to be a cross-age phenomenon.</p>
29	RCGP		<p>Question 2. The statement is correct to state ‘People ... are offered an urgent direct access upper gastrointestinal endoscopy.’ There is no way of coding an offer of endoscopy, rather than a referral. (DJ)</p>
1	University Hospitals Bristol NHS Foundation Trust		<p>I would recommend rephrasing this standard to allow healthcare systems to achieve the same outcome but through an alternative mechanism. Many Trusts offer straight-to-test endoscopy within 2 weeks via the 2WW referral system which has exactly the same outcome as direct access (endoscopy within 2 weeks of referral – and often a lot sooner). It is also a safe, well established system that enables patients to be tracked and very rapid onward management of patients who are diagnosed with cancer. I believe direct access would be a less safe mechanism, introduce delays further down the pathway, and do nothing to change the speed of endoscopy (we aim to scope 90% 2WW OG cancer referrals within 7 days of the referral arriving). A better standard would be to say people presenting with symptoms of OG cancer are offered an upper GI endoscopy within 2 weeks of referral – rather than specifying that has to be achieved through direct access, when systems exist already in the country that offer this service without needing to bring in something different. The important thing is that the right patients get a test within 2 weeks – that doesn’t have to be done through direct access. It is exactly the same outcome and would have exactly the same quality benefits.</p> <p>You would need a way of measuring the denominator in primary care i.e. how many people present with symptoms of OG cancer. Trusts can tell you how many 2WW referrals for endoscopy they get (assuming the patients are not referred via direct access, where it is much harder to get accurate information here as the onus remains on GPs – so another good reason to rephrase the standard as I suggest and make it more measurable) but not how many people were seen by GPs with symptoms who were not referred.</p>



<p>12</p>	<p>Oesophageal Patients' Association</p>	<p>Section 1 Introduction or quality statement 1 (measure). Pages 9 and 10.</p>	<p>Recommend deleting the age criterion of "aged over 55" to read: -- " Symptoms that might be caused by oesophageal or stomach cancer are problems with swallowing, weight loss combined with reflux, (when a feeling of acid burning spreads upwards in the chest) or with indigestion ( also called dyspepsia) or with abdominal pain." References leading to this suggestion follow.</p> <p>The clinical treatment of cancers of the oesophagus is advantaged if they are detected and treated early. This leads to improved survival following complete removal of tumours by less invasive endoscopic means.</p> <p>Reynold JV et al. <a href="#">Evolving progress in oncologic and operative outcomes for esophageal and junctional cancer: lessons from the experience of a high-volume center. J Thorac Cardiovasc Surg.</a> 2012;143(5):1130-1137.e1. doi: 10.1016/j.jtcvs.2011.12.003. Epub 2012 Jan 11.</p> <p>Earlier detection, treatment and survival result from better surveillance of the known precursor lesion of esophageal adenocarcinoma, Barrett's Oesophagus.</p> <p>Grant KS et al. <a href="#">Effect of Barrett's esophagus surveillance on esophageal preservation, tumor stage, and survival with esophageal adenocarcinoma. J Thorac Cardiovasc Surg.</a> 2013;146(1):31-7. doi: 10.1016/j.jtcvs.2012.12.058. Epub 2013 Jan 11.</p> <p>El-Serag HB et al. Surveillance endoscopy is associated with improved outcomes of oesophageal adenocarcinoma detected in patients with Barrett's oesophagus. <a href="#">Gut.</a> 2015 pii: gutjnl-2014-308865. doi: 10.1136/gutjnl-2014-308865. [Epub ahead of print]</p> <p>The age of onset of chronic gastro-oesophageal reflux disease [GORD] predicts the age of onset of Barrett's oesophagus, the known precursor for oesophageal adenocarcinoma. GORD symptoms are frequent at less than 30 years.</p> <p>Thrift AP et al. Age at onset of GERD symptoms predicts risk of Barrett's esophagus. <a href="#">Am J Gastroenterol.</a>2013;108(6):915-22. doi: 10.1038/ajg.2013.72. Epub 2013 Apr 9</p> <p>7% of cases of Barrett's oesophagus occur in family clusters and these were younger at the onset of heartburn and oesophageal adenocarcinoma. This is a not-inconsiderable portion of Barrett's patients.</p> <p>Verbeek RE et al. Familial clustering of Barrett's esophagus and esophageal adenocarcinoma in a European cohort. <a href="#">Clin Gastroenterol Hepatol.</a> 2014;12(10):1656-63.e1. doi: 10.1016/j.cgh.2014.01.028. Epub 2014 Jan 28.</p> <p>Current BSG Guidelines state that endoscopic screening for chronic GORD patients should be considered on multiple factors: 'greater than 50 years, white race, male gender and obesity with a lower threshold in families with a first degree relative with Barrett's oesophagus or oesophageal adenocarcinoma'.</p> <p>Fitzgerald RC et al. British Society of Gastroenterology guidelines on the diagnosis and management of Barrett's oesophagus. <a href="#">Gut.</a> 2014 Jan;63(1):7-42. doi: 10.1136/gutjnl-2013-305372. Epub 2013 Oct 28.</p> <p>The NICE Guideline CG184. Pub. 3 September 2014.is at odds with the current draft under consideration P16. of CG 184 states 'consider referral to a specialist service for people of any age with gastro-oesophageal symptoms that are not responsive to treatment or unexplained.' And for Barrett's risk factors----- 'older age'. CG184 and the NICE Quality Standard 'Suspected Cancer' GID-QSD140 should be in concordance. Therefore I suggest dropping the age criterion 'aged over 55' made in the top box of this comment.</p>
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13	Norfolk and Norwich University Hospitals NHS Foundation Trust		Yes this reflects the crux of the problem and a proposed solution
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		No detail is given on this other than “local data collection” – presumably this will have to be managed by Primary Care as they will be requesting the direct access requests
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		We run a straight to test service for suspected upper/lower GI cancers at NNUH however these are managed through the 2WW route and not through direct access
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		Should be targeted at those at high risk of OG Cancer/HGD/LGD/Barrett’s – e.g. patients regularly taking relief for acid reflux/heartburn – demographic factors (male, white, over 50, overweight, high alcohol consumption etc.)
14	British Society of Gastroenterology (BSG)		Although this will shorten the pathway to diagnosis, patients that fulfil these criteria have advanced disease with a 5 years survival of <10%. Therefore the current statement that “Early detection and time taken to diagnosis can improve the quality of life for people with oesophageal or stomach cancer and is critical for successfully treating and surviving cancer” may need to be reconsidered in light of our comment. Admittedly the pressure on endoscopy services are increasing, however a more inclusive approach should be considered within the evidence base, with the aim of diagnosing cancers at an earlier stage.
20	NHS England		The first QS is a good one and fits with the cancer programme’s work to establish a new performance standard that patients wait no longer than four weeks from initial referral by a GP to diagnosis or ruling out of cancer well.
20	NHS England		Measuring direct access to gastrointestinal endoscopy within 2 weeks may be superseded by the new 28 day Faster Diagnosis Standard, in which full diagnosis will be required within 4 weeks
25	British Medical Association	Question 1	Yes, but to ensure appropriate timely treatment emphasis needs to be on the whole patient journey, including the periods before presentation, after presentation, before referral, and after referral. Patient and doctor awareness of the symptoms and signs of early cancer is vital and having good quick access to diagnostics is essential. Patient experience is important, and in particular, anxiety should be minimised. Patients need early access to their GP and rapid referral for further investigation and treatment. Delay can, of course, exacerbate symptoms and lead to emotional distress. GPs’ concerns about the lack of available appointments and time within which to care for patients are well documented. If quality standards are to be met, these concerns need to be addressed urgently.
25	British Medical Association	1	Support

29	RCGP	General point	<p>I understand why the emphasis is on time to cancer diagnosis. But GPs (to whom this standard seems mostly to be directed) are only able to influence the time to referral, or at most the time to being seen by specialists. Any delays beyond that point are outside the control of primary care. For those commissioning care it will be important to distinguish between the two.</p> <p>On p2 it says that the quality standard is expected to contribute to improvements in outcomes including 'time to cancer diagnosis'. From memory the National Cancer Audit carried out a few years ago by Greg Rubin and colleagues showed that overall GPs' responses to symptoms suggestive of cancer was good. Is it clear that this standard is required at all? (DJ)</p>
29	RCGP		<p>Difficulty is in the interpretation of the phrase 'with symptoms that suggest oesophageal or stomach cancer'. For instance if a patient presents with new dyspepsia, but with a history of recent NSAID use, it would be reasonable to stop the NSAID; treat with standard anti-dyspepsia treatment; and wait for 2 weeks before deciding if endoscopy is needed. Are the architects of this standard happy that adopting it is likely to increase referrals for endoscopy with marginal indication? (DJ)</p>
29	RCGP		<p>Question 1. Is there evidence to suggest that this is a key area for quality improvement? From the National Audit, and from data collected in the general practice this particular cancer was not one associated with long delays to diagnosis. (DJ)</p>
29	RCGP		<p>I cannot see how the denominator data could be collected. I suspect the only way will be for the denominator to be those referred by a GP for suspected upper GI cancer hence this would in fact measure availability of 2 week wait direct access endoscopy rather than the proportion of those with suggestive symptoms who get 2WW upper GI endoscopy: "those with suggestive symptoms" will be hard to measure as GPs are not good at coding individual symptoms. The rate of referral of patients the GP suspects to have upper GI malignancy will be almost all (exception being those who decline or who investigation would be inappropriate for) this is different to the number with suggestive symptoms. Basically if the GP suspects they will refer but there maybe patients with "suggestive symptoms" in who the GP, rightly or wrongly, does not suspect malignancy. It is also worth noting that upper GI endoscopy is an invasive procedure and there are cases where it is appropriate for the patient to see a consultant to decide if this is the most appropriate investigation for them or not rather than going for the direct access endoscopy. (RM)</p>

35	Oesophageal Cancer Westminster Campaign		<p>The Oesophageal Cancer Westminster Campaign generally supports this quality standard as there is a great need to improve the speed at which patients with oesophageal cancer are diagnosed and treated.</p> <p>Key reasons for this are:</p> <ul style="list-style-type: none"> <li>• Oesophageal cancer is the 4th highest cancer killer of men in the UK</li> <li>• Survival rates are less than 15% over 5 years</li> <li>• The UK has the highest incidence of oesophageal adenocarcinoma in the world</li> <li>• The number of people diagnosed in the UK is rising every year.</li> <li>• Outcomes are significantly better for patients diagnosed at earlier stages - around 67% of those diagnosed at the earliest stage survive for at least five years compared with 3% for those diagnosed at a late stage.</li> </ul> <p>This makes early diagnosis and treatment essential and all efforts to improve this are vital.</p>
35	Oesophageal Cancer Westminster Campaign		<p>We believe that the quality standard would improve if Barrett's oesophagus was recognised as a pre-cursor condition and that the following should be recognised as conditions that warrant urgent action:</p> <ul style="list-style-type: none"> <li>• Barrett's oesophagus</li> <li>• Low grade dysplasia</li> <li>• High grade dysplasia</li> </ul> <p>Reflux (heartburn) is a symptom associated with these conditions but the quality guidance should explicitly state that these three conditions that indicate potential oesophageal cancer. The long term risk of somebody with Barrett's oesophagus developing cancer is small - 0.3% per patient year, but this accumulates so that somebody developing Barrett's aged 30 will have an 11 - 25% risk of developing adenocarcinoma before the age of 80. The same is true of both high grade and low grade dysplasia and patients with these conditions should be investigated for oesophageal cancer, as well as kept on surveillance if the initial test is negative.</p>
35	Oesophageal Cancer Westminster Campaign		<p>The quality standard should also specify the use of a white light as the gold standard for gastrointestinal endoscopy since trans-nasal endoscopy, which is increasingly being used in community services, gives much poorer quality images and may not be appropriate for fast-track referrals.</p>
35	Oesophageal Cancer Westminster Campaign		<p>We believe that the quality standard needs to call for a nationally accepted pathway for oesophageal cancer patients, developed by Clinical Commissioning Groups for Trusts to follow. One model that could be used is the British Society of Gastroenterology's pathway 'Guidelines for the Management of Oesophageal and Gastric Cancer'.</p>

35	Oesophageal Cancer Westminster Campaign		<p>We believe that the quality standard should encourage Trusts to improve the recording of oesophageal cancer and other oesophageal conditions. This collection of data should cover not only total numbers of those with oesophageal conditions, but also the type and stage, and that a focus is needed as too many patients are not being recorded in the correct way and are being lost in the system. Improvements in services are needed and having the correct data is a large part of ensuring improvements.</p> <p>As part of this increase in measurement, all diagnosed cases of Barrett's oesophagus should be registered with the UK Barrett's Oesophagus Registry in order that large cohort studies can continue to facilitate optimisation of management pathways.</p>
37	Cancer Research UK		needs to be broadened to include a range of tests that should be available through direct access.
37	Cancer Research UK		<p>Direct Access</p> <p>We recommend that the quality statement lists all the specified diagnostic tests that should be directly accessible by GPs, to ensure they are universally commissioned and GPs are aware of what should be available to them.</p> <p>With regards to the selected quality standards, we feel that direct access is partially addressed by statement 1, but the scope is narrower than what may have been expected given the other direct access tests recommended in the guidelines. Whilst welcoming the quality statement which prompts GPs to utilise direct access upper GI endoscopy, and thereby provides impetus for this to be commissioned, we are conscious that this does not fully address the issue that GPs should have direct access for several other tests, which therefore may be seen as less important.</p> <p>The need for direct access to certain key tests was highlighted in the cancer strategy, which stipulated that 'NHS England should mandate that GPs have direct access to key investigative tests for suspected cancer – blood tests, chest x-ray, ultrasound, MRI, CT and endoscopy – by the end of 2015'<sup>3</sup>. This has not yet occurred. As at the end of 2014, only 30% of CCGs commissioned direct access to all four specified diagnostic tests (chest x-ray, non-obstetric ultrasound, endoscopy and brain MRI), and 22% of CCGs commissioned none of these<sup>4</sup>.</p> <p>As the average GP will see fewer than 8 new cases of cancer per year<sup>5</sup>, it is vital that GPs have the appropriate tools at their disposal to support them with the task of identifying or ruling out cancer. By only emphasising one direct access test for GPs within the quality standard, we feel this misses an opportunity to highlight that several tests should be available, built into commissioning plans and utilised appropriately by all GPs, thereby helping to eliminate the current variation.</p>

<sup>3</sup> Achieving World Class Cancer Outcomes: a Strategy for England, 2015 – 2020 (2015) Independent Cancer Taskforce

<sup>4</sup> See <http://www.gponline.com/exclusive-half-gps-denied-access-cancer-scans/article/1322870>

<sup>5</sup> Calculated by the Statistical Information Team at Cancer Research UK using 2011 UK cancer incidence and 2011 NHS workforce data on the total number of GPs in the UK.

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7	British Thoracic Society		This refers to direct access for oesophageal symptoms but appears to have little evidence to support it with the statement in the rationale of “may lead”. Important to ensure that there is an evidence base prior to undertaking such a NICE statement.
20	NHS England		The second QS is very controversial and not highest priority. There is significant controversy about use of FOB in primary care. The NICE guidance on this aims it at an intermediate risk group but this is not clear in the QS as written. FOB has only around 50% specificity and sensitivity and may provide false reassurance. People with Fe deficient anaemia need top and tail endoscopy, not FOB. One alternative may be to use a Faecal Immunochemical Test (FIT) rather than FOB, but further expert advice should be sought from the colorectal CRG before such a decision were made. The UK National Screening Committee has just recommended FIT for use instead of FOBT, although this does not cover management of symptomatic patients.
29	RCGP		The denominator here is very complex and difficult to get data on as GPs do not code symptoms reliably. Availability of this test outside of screening for use by GPs would be an easier thing to measure improvement in at this point in time. Even if symptoms were coded many of those with for example “unexplained weight loss <60 years” will need referral under a 2WW pathway for colorectal or other investigation rather than FOB testing. (RM)
1	University Hospitals Bristol NHS Foundation Trust		This is a reasonable standard which applies mainly to primary care. Primary care would need to advise on whether it can be measured as this one sits outside the acute sector. We could provide numbers referred for FOBT although we may not know if these were all suspected cancer cases (although I think it’s usually done specifically to exclude cancer).
10	Vale Royal CCG		FOB testing is not available locally and even if it was available may miss many cancers. The new FIT test has not been evaluated. We feel it is not helpful to include this as a quality measure as it may delay diagnosis (as patient has to submit the test) and is falsely reassuring in many cases. We feel it would also lead to confusion as to who qualifies for it and who should have an urgent referral or endoscopy/CT colonography
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		This highlights an issue, though there has been some debate around the efficacy of FOBT versus FIT techniques and the standard should consider this
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		The proposed indicator of “time to diagnosis” will not show whether this is a more efficient route to diagnosis than 2WW referral – the two need to be compared (standardised for stage of disease). Diagnosis dates would not be collected in Primary care so this data would have to be collected by Secondary Providers, however data items to identify the direct access patients would need to be available, such as a new value in the attribute SOURCE OF REFERRAL FOR OUT-PATIENTS
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		Comparison should be made to the benefits and challenges of the National Screening Programme

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13	Norfolk and Norwich University Hospitals NHS Foundation Trust		Agree with the proposal
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<p>14</p>	<p>British Society of Gastroenterology (BSG)</p>	<p>The BSG very strongly recommends that this statement is rejected. There is no good evidence that FOB testing is useful in suspected bowel cancer, ie patients who are symptomatic. In addition, there is concern that this recommendation could lead to patients being referred for a poor quality test and could lengthen the time to receiving a definitive diagnosis. Such is the degree of concern from the BSG membership regarding the guidance that many members have, in discussion with commissioners, agreed not to implement this element of the guidance.</p> <p>We attach more detailed comments from our senior members to justify our recommendation:</p> <p>The evidence for FOBt suggests that it is a useful screening test in an asymptomatic population, and evidence does not exist to recommend it in a symptomatic population. FOBT has low specificity, sensitivity, PPV and NPV, and is not a suitable investigation in those with symptoms or anaemia. Evidence demonstrates that this test will miss approximately 50 per cent of cancers in a screening setting, compared to a 95 per cent detection rate for colonoscopy.</p> <p>From CG27 NICE guidelines page 126 (Suspected cancer: recognition and referral) "Faecal occult blood (6 studies, N = 9871 of which at least 3 studies considered a positive FOB test result to be if any of 3 tested faecal samples were positive) conducted in symptomatic patients presenting in a primary care setting is associated with sensitivities that ranged from 0-84%, specificities that ranged from 76-87%, positive predictive values that ranged from 0-16%, and false negativity rates that ranged from 16-100% for colorectal cancer. All the studies were associated with 1-5 bias or applicability concerns (see also Table 29)."</p> <p>Surely this is not the basis on which to make a recommendation?</p> <p>CG27 guidelines suggest that patients with a negative test are discharged from follow up (flow chart page 130)</p> <p>It is therefore entirely inappropriate to recommend the use of FOBt in symptomatic patients.</p> <p>There is also a concern about significant variation in the quality assurance of laboratory testing for FOBt, as several different assays are currently used in the UK of varying quality, thus the bowel cancer screening programme FOBt testing takes place only in screening hubs where are monitored by NEQAS. The number of stool samples tested has not been made clear in either the guidelines for suspected colorectal cancer referral, or the proposed new quality standard.</p> <p>We are very concerned that this recommendation could lead to patients being referred for a poor quality test and could lengthen the time to receiving a definitive diagnosis.</p> <p>The fact that there were many objections to this aspect of CG27 from many different sources appears not to have impacted on the decision to press ahead with this recommendation, and there is clearly a concern that this quality standard will compound this error of judgement.</p> <p>The FOB proposal however should be strongly opposed as it is not evidenced based as using the data provided in the NICE guidelines there was a sensivity of only 50% indicating that NICE were recommending a test that they know is incorrect in 50% of cases – this is not clinical excellence!</p>
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16	Manchester Cancer		<p>Manchester Cancer Colorectal Pathway Board wholly disagrees with this statement as a NICE quality standard. There are significant national concerns regarding the use of the currently available guaiac faecal occult blood test as a tool to aid referral (BMJ Aug 15 2015, Prof R Steele et al). Current use of this test runs the risk of false reassurance in the symptomatic patient group and underreferral whereas the role of faecal immunochemical testing is currently the subject of ongoing research.</p> <p>In order to aid early diagnosis of colorectal cancer, Manchester Cancer, after discussion in the Colorectal Pathway Board, and similar to other large cancer management groups (London Cancer, London Cancer Alliance) have decided to go beyond NICE guidance in this regard and instead of offering faecal occult blood tests to the groups listed in NG12, offer urgent two week wait assessment and investigation as appropriate.</p> <p>Until the role of faecal immunochemical testing is defined and its use clearly recommended in relevant groups (including age, sex, relevant level of Hb cutoff) the use of this quality standard should not be considered by NICE and its introduction is a negative step – representing a total waste of money for a test that is inadequate to exclude cancer in a symptomatic patient.</p>
20	NHS England		<p>Referral information is collected already. However, data on people who present and are not referred are not collected routinely. This may be difficult to collect – it would rely on GPs identifying patients they think meet the criteria for referral, but whom they have obviously not referred. Presumably, this would only happen in a situation where the clinician felt they had a legitimate clinical reason for non-referral, and so should not be counted as 'poor quality'. It should be possible to collect data on the information given to patients.</p>
24	Association of British Neurologists	Question 2	<p>If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?</p> <p>Yes</p>
25	British Medical Association	2	<p>FOB testing is not routinely accessible to GPs in all areas, and if this is to be a quality standard aimed at practices this service must be commissioned. The presence of a negative test must not overrule clinical judgement.</p>
26	Bowel Cancer UK	Introduction	<p>We know that the symptoms of bowel cancer that people present to their GP with can be vague but serious, which makes the decision of when to refer for diagnostic testing a difficult one. Our research has shown that one in five respondents reported seeing their GP more than three times before being referred for an endoscopy. So we welcome a test that can be carried out quickly in primary care to ascertain whether an individual should be referred for further testing or given the all clear.</p>
26	Bowel Cancer UK	Introduction	<p>However people who experience symptoms where bowel cancer is suspected should be referred for the most reliable and accurate diagnostic test available. Ensuring individuals have the right test for them is essential if we are to increase the number of people diagnosed in the early stages of the disease. Being referred for the right test first time will help to reduce the chances of having to have repeated testing, which can be stressful for the individual and costly to the NHS.</p>

26	Bowel Cancer UK		<p>The draft QS states that: “Adults presenting in primary care with symptoms that suggest colorectal cancer who do not have visible rectal bleeding, have a test for occult blood in faeces.” While there is increasing evidence in support of using FOBTs to identify those at higher risk of having bowel cancer, we would argue that this test needs to be FIT rather than the guaiac FOBT. During the consultation for the NICE guideline on the Referral for Suspected Cancer (NG12) we and other several groups expressed serious reservations about this recommendation leading to the use of the gFOBT, in the specified groups. This recommendation was also widely criticised in a letter to the BMJ (<a href="http://www.bmj.com/content/350/bmj.h3044/rr-0">http://www.bmj.com/content/350/bmj.h3044/rr-0</a>) but, despite this, no change was made to the final document. The reasons for this objection was outlined as follows:</p> <ul style="list-style-type: none"> <li>• Current NICE guidance on anaemia states that men and non-menstruating women of any age with unexplained iron-deficiency anaemia should be referred urgently for upper and lower gastrointestinal investigation.</li> <li>• The guideline does not specify which FOBT is recommended. The only FOBT currently available in the UK is the guaiac test, which detects no more than 50% of CRC.</li> <li>• The guaiac FOBT-based UK CRC screening programmes requires a number of stool samples and reliable interpretation of the FOBTs is only possible in laboratories with dedicated staff where strict quality assurance is employed. The guaiac FOBT should only be used in this context and for population screening only.</li> <li>• Anyone seeking advice about symptoms wishes reassurance that there is no serious disease. The guaiac FOBT is not sufficiently sensitive for this purpose and as negative tests do provide reassurance diagnosis is likely to be delayed.</li> <li>• This comes at a unfortunate time as evidence is rapidly accumulating that quantitative faecal immunochemical testing (FIT) - used at an appropriate cut-off of concentration - can provide a valuable means of triaging symptomatic patients, including those who currently warrant urgent referral.</li> </ul>
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26	Bowel Cancer UK		<p>NICE documented, in NG12, that the evidence for the use of gFOBT in assessment of the symptomatic was weak and that the newer FIT may have advantages. Furthermore, gFOBT are now clearly considered to be obsolete for population screening and both Scotland and England are evolving their bowel cancer screening programmes from gFOBT to FIT. The following advantages of FIT in a screening setting, also apply in the assessment of symptomatic patients:</p> <ul style="list-style-type: none"> <li>• FIT is easier to use and can be measured more reliably using a machine rather than the human eye</li> <li>• FIT is sensitive to much smaller amount of blood than gFOBT and therefore can detect cancers more reliably and at an earlier stage,</li> <li>• the increased sensitivity enables FIT to detect more pre-cancer lesions (advanced adenomas,</li> <li>• FIT requires a single faecal sample and is more acceptable to invited subjects which markedly increases participation rates</li> <li>• FIT is a cost effective alternative to gFOBT.</li> </ul> <p>The accuracy of FIT means that a negative test result would provide considerable reassurance to both patients and GPs that an urgent referral for colonoscopy is not required. The adoption of FIT could help to direct scarce colonoscopy resource to those who would most benefit.</p>
26	Bowel Cancer UK		<p>Although no test is perfect and there is still more work required on the use of FIT in primary care, the NICE Diagnostics Advisory Committee on 'Faecal immunochemical tests to triage low risk populations for suspected colorectal cancer referrals in primary care' will help to address many of the unresolved issues. We would urge NICE to wait until there is NICE has completed the guidance on the use of FIT. During this time there is also likely to be further evidence on the use of FIT in primary care from the pilot that is being undertaken in Tayside, Scotland (<a href="http://news.scotland.gov.uk/News/Bowel-test-pilot-to-enhance-early-detection-of-cancer-1ff4.aspx">http://news.scotland.gov.uk/News/Bowel-test-pilot-to-enhance-early-detection-of-cancer-1ff4.aspx</a>).</p>
26	Bowel Cancer UK		<p>In conclusion, we do not believe QS2 will contribute to driving measureable improvements to the outcomes outlined in the QS i.e. 'time to diagnosis,' and 'cancer mortality' as we believe that QS2 will encourage adoption of the gFOBT until there is NICE guidance on the use of FIT.</p>
29	RCGP		<p>On p10 the features are spelt out. New dyspepsia over the age 55, without any other explanation (see above) should raise doubts of cancer, before any weight loss occurs. If the standard is implemented, is there a danger that patients without weight loss will not be referred, therefore lengthening time to diagnosis? (DJ)</p>
29	RCGP		<p>Regarding this statement on p5, NICE guidelines on cancer there was an economic analysis comparing faecal occult blood testing and endoscopy. However it is not consistent with the NICE guideline on suspected cancer which advises 2 week wait referral for various clusters of symptoms (<a href="http://pathways.nice.org.uk/pathways/suspected-cancer-recognition-and-referral/suspected-cancer-recognition-and-referral-site-or-type-of-cancer#content=view-node%3Anodes-gastrointestinal-tract-lower-cancers">http://pathways.nice.org.uk/pathways/suspected-cancer-recognition-and-referral/suspected-cancer-recognition-and-referral-site-or-type-of-cancer#content=view-node%3Anodes-gastrointestinal-tract-lower-cancers</a>, accessed 27 Jan 2016).</p> <p>For a patient with symptoms suggesting cancer, and who has normal haemoglobin, and normal ferritin, the critical standard is referral for endoscopy, not tests for faecal occult blood. (DJ)</p>

29	RCGP		<p>On p13 it is suggested that patients over 60 with anaemia, but in the absence of iron deficiency, should be offered faecal occult blood testing. This is simply encouraging bad medicine. If there are other features to suggest cancer then (as above) the recommendation would be to refer for endoscopy. If there are no other features to suggest cancer, then the clinician should be looking for the cause of the anaemia, which in these circumstances is unlikely to be colonic cancer. For a microcytic anaemia one can just about justify faecal occult blood testing, but for other types. Are the authors seriously suggesting that a patient over the age of 60 with macrocytic anaemia should have faecal occult blood testing? I also wonder whether any self-respecting laboratory would process such requests. (DJ)</p>
29	RCGP		<p>This is not reflective of current NICE guidance which suggests there is a small group of patients where this is appropriate: Age &gt;50 with unexplained abdominal pain or weight loss OR aged under 60 with changes in bowel habit or iron deficiency anaemia or over 60 with anaemia even without iron deficiency (NICE guidance 2015). This is not the same as “Adults presenting in primary care with symptoms that suggest colorectal cancer who do not have visible rectal bleeding” and in fact many of these will meet the criteria to have colonoscopy which should not be delayed by waiting for faecal occult blood testing. To be reflective of a key area of quality improvement this would need to be written in a more specific way. Given the lack of access to this test outside screening for many GPs at the moment it would perhaps be more appropriate in the 1st instance to target this at CCGs with an aim of improving the availability of this test to those in primary care where it is appropriate. Later the guidance is clarified but this needs to be clearer in the initial statement to avoid significant confusion as this is not All “Adults presenting in primary care with symptoms that suggest colorectal cancer who do not have visible rectal bleeding”. (RM)</p>
3	South Sefton CCG		<p>Adults presenting in primary care with symptoms that suggest colorectal cancer who do not have visible rectal bleeding, have a test for occult blood in faeces.  I think this statement is misleading  It should read certain patients....  There is a risk otherwise that all patients with no rectal bleeding will be managed in this way regardless of their other symptoms which should trigger an urgent referral.  Given that FOB have a sensitivity of 60% and specificity of 60% there is a real risk of false negatives and along with false positives.  It should also be noted that FOB as a laboratory test is not widely available and its use in symptomatic patients questionable.  It is likely that FIT will provide a more robust test but requires further research.</p>
37	Cancer Research UK		<p>should specify that the Faecal Immunochemical Test should be used, rather than guaiac Faecal Occult Blood Test.</p>

37	Cancer Research UK	<p><b>Eliminating Unwarranted Variation</b>  This quality statement should make it clear that FIT should be the preferred test. FIT must be commissioned and used for adults presenting in primary care who do not meet the criteria for an urgent suspected lower GI cancer referral.</p> <p>NG12 aims to reduce unwarranted variation in referral practice, and improve performance in this regard. Efforts to eliminate unwarranted variation would be hugely impactful – as one participant in our recent roundtable said: “if we just raise everybody up to a certain bar that would have far more impact than changing where the bar is.” If all the regions of England were as good as the South West at diagnosing cancer early nearly 20,000 more patients over two years could be diagnosed at stage 1 or 2, giving them a better chance of survival.<sup>6</sup></p> <p>There is some ambiguity within the guidelines which could contribute to variations in practice. One such example relates to the testing for occult blood in faeces. This quality statement does not specify what test should be used and there are two potential options: the guaiac faecal occult blood test (FOBT), or the faecal immunochemical test (FIT). While we appreciate that NICE will be putting together guidelines on the use of FIT in symptomatic patients<sup>7</sup>, existing evidence suggests that FIT is a preferable test to FOBT, and the NICE quality standard should reflect this. Use of FOBT is problematic as its high level of false negatives can lead to real harm if patients receive unwarranted reassurance through a false negative test result.</p> <p>The recent UK National Screening Committee recommendation for FIT to replace FOBT within the bowel screening programme will also cause problems for the ongoing used of FOBT in symptomatic patients. We expect this recommendation will receive ministerial approval and therefore capacity and expertise in the system to analyse FOBT will reduce significantly in the near future.</p> <p>As the quality standard has not specified the use of FIT, this ambiguity causes confusion and may also cause hesitation in commissioning any provision of testing for occult blood in faeces, which is the worst possible outcome. If NG12 indicates that a patient’s symptoms would warrant some action but they are not tested for occult blood, then they should be escalated to a colonoscopy rather than no action being taken.</p>
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<sup>6</sup> Analysis conducted by Cancer Research UK, October 2015. See <http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2015-10-28-where-cancer-patients-live-could-influence-late-diagnosis>

<sup>7</sup> See <http://www.nice.org.uk/guidance/cg131> (accessed February 2016)

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37	Cancer Research UK		<p>To measure the 'proportion of presentations of symptoms that suggest colorectal cancer, without visible rectal bleeding who have a test for occult blood in faeces', the denominator would need to be based on read code definitions: without read codes it would be very unlikely this could be measured.</p> <p>The outcome measure of 'the time to colorectal cancer diagnosis' could possibly be linked to current work from the cancer strategy which is currently undergoing testing – to give a definitive diagnosis (or the all clear) within 28 days of the initial referral. To measure would need a combination of sources which are currently combined through the cancer analysis system. Analysts based in Public Health England (formerly the National Cancer Intelligence Network) are undertaking an exploratory project to understand intervals, but this could be further refined to develop a metric if required.</p>
7	British Thoracic Society		Testing for occult blood in faeces should happen routinely anyway in part related to the bowel cancer screening so this too seems somewhat of a “weak” quality standard.
9	Association of Clinical Pathologists		There is a very strong feeling in the Chemical Pathology community that ONLY immunoassay based testing for faecal occult blood should be recommended and the guaiac (colorimetric) based tests should no longer be used.
1	University Hospitals Bristol NHS Foundation Trust		I would wholeheartedly support this as a standard and something that will really help patients and services to ensure people get referred in a timely way and have the right information to make informed decisions about their care. I think it will be very difficult to measure. You will need to define a clearer metric for how this will be demonstrated by GPs and easily measured.
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		Agree wholeheartedly that this is an issue – causing delay to the patient’s pathway and Cancer 62 day performance to fall.
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		Agree with the outcomes – performance should be presented at a CCG level and these organisations held accountable for any deviation below the national average. CCG’s should also be held accountable to deliver a decrease in the number of Cancer Waiting Times breaches caused by patient initiated delay – these can be identified from the CWT dataset.
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		A new patient information leaflet and 2WW referral forms have recently been introduced here across the East of England Strategic Clinical Network although their implementation and efficacy has not been monitored yet.
13	Norfolk and Norwich University Hospitals NHS Foundation Trust		There should be consistency of language used – not all patients understand terms such as “lesion”, “sinister cause” etc. that are often used in clinical parlance, however, all should understand the phrase “referral to rule out or confirm cancer”

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15	Royal College of Paediatrics and Child Health		<p>We feel that this is written from a very adult standpoint. There will be a number of children and very young people to whom these questions are inappropriate, yet the idea (“Was the referral made with clarity and sufficient information”) is very relevant.</p> <p>Could the wording be altered to reflect “and the carers of young children”, and make reference to a variety of different techniques to collect data from young people being needed to capture their experiences?</p>
17	Faculty of General Dental Practice (UK)		<p>The NHS leaflet entitled “Patient information for urgent referrals” (available at <a href="http://www.londoncanceralliance.nhs.uk/media/89869/patient-information-for-urgent-referrals-revised-january-2015.pdf">http://www.londoncanceralliance.nhs.uk/media/89869/patient-information-for-urgent-referrals-revised-january-2015.pdf</a>) is an excellent one-page resource aimed at patients who are being urgently referred by a GP or dentist for suspected cancer.</p> <p>All dentists should be advised of the availability of this leaflet through relevant bodies (including their professional bodies). Without such a resource of professionally pre-prepared information, healthcare professionals’ attempts to reassure, support and encourage attendance by patients, all without causing alarm, may fall short. Provision of this leaflet, or something equivalent, should be adopted into the quality standard to encourage the commissioning of services providing such a high quality resource.</p>
18	British Dental Association	implications	<p>Central provision of patient information, or signposting to appropriate resources, would be helpful and efficient. For example, the “London Cancer patient information for urgent referrals” could be adopted by commissioners and disseminated.</p>

19	Teenage Cancer Trust	Question 3	<p>We support the inclusion of this Quality Statement. Patients who have a poor understanding of their condition and treatment report worse patient experience. In order for this Quality Statement to apply equally to all patients within its scope (children, young people and adults), it should be amended to include a requirement for information to be provided in an age-appropriate manner and tailored to the patient's level of understanding of their condition. This should be noted within the Rationale and the Equality and Diversity Considerations.</p> <p>Young people report a lower understanding of their condition and stage of treatment than older age groups; only 49% of 16-25 year olds completely understood what was wrong with them when it was first explained compared to an average of 74%<sup>8</sup>.</p> <p>We have anecdotal evidence that using age-appropriate language and patient information would improve the diagnosis experience for young people, who often don't understand phrases like 'malignant' or 'neoplasm'. Natasha's story demonstrates this: "I was diagnosed with Hodgkin's Lymphoma. The doctor said 'it's a disease of the lymph nodes, but it's treatable'. Before this, an infection had been mentioned, so initially I shrugged it off and assumed I'd just get antibiotics. My diagnosis was so vague, there was no mention of the word 'cancer' at all! I didn't really understand what was wrong with me. It was when I phoned a family friend that it all became clearer. She told me over the phone that Hodgkin's Lymphoma was a type of cancer, and gave me more information about it. I felt awful for her that she had to give me the full news. When I found out that I had cancer, I just cried."</p>
2	OPAAL UK	P18	<p>We are pleased to see reference on p.18 to the role advocacy can play in supporting communication, this standard would be strengthened by a greater emphasis on encouraging advocacy referrals and could read "people with suspected cancer should be offered advocacy support"</p>
20	NHS England		<p>The third QS principle important but could be worded better – people with suspected cancer often not referred directly to a spec cancer service but to a diagnostic test or to a specialty OPD that is much broader than cancer (e.g. gastro or colorectal clinic).</p>

<sup>8</sup> Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey



22	Teenagers and Young Adults with Cancer (TYAC)		<p>We support the inclusion of this Quality Statement. Patients who have a poor understanding of their condition and treatment report worse patient experience. In order for this Quality Statement to apply equally to all patients within its scope (children, young people and adults), it should be amended to include a requirement for information to be provided in an age-appropriate manner and tailored to the patient's level of understanding of their condition. This should be noted within the Rationale and the Equality and Diversity Considerations.</p> <p>Young people report a lower understanding of their condition and stage of treatment than older age groups; only 49% of 16-25 year olds completely understood what was wrong with them when it was first explained compared to an average of 74%<sup>9</sup>.</p>
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<sup>9</sup> Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey

25	British Medical Association	3	<p>Effective communication with patients at stressful times challenging; some patients are referred for further investigation, which results in a 'clear' diagnosis. We agree that any information provided needs to be carefully balanced to avoid any unnecessary anxiety, while providing patients with sufficient information to prioritise attendance at the clinic within their other activities. It is also important that once patients have received their initial referral they know, if they are subsequently re-referred, to where and why that is happening, and what are the expected time-frames for being contacted. If a non-malignant diagnosis is made the arrangement made for the ongoing care of the patient need to be clearly explained.</p> <p>Recent qualitative research commissioned by the BMA found that many doctors felt they had insufficient training in communication and listening in order to have difficult conversations – and although this was specifically in the context of having conversations with patients approaching the end of life, these concerns extend to having conversations with patients at a much earlier stage of the disease progression. In providing information to help people with suspected cancer understand the importance of attending a specialist appointment, it is crucial to ensure that doctors are adequately trained and supported in initiating and holding difficult conversations with patients. It is not, however, solely an issue of education and training and doctors must also be supported by senior colleagues and managers to have the time and quiet space in which such conversations can take place. This is particularly important in the context of early referrals in allowing patients to ask questions, to reassure them, and to alleviate any fears or concerns they may have.</p> <p>Full details of the public dialogue research can be found on the BMA website at: <a href="http://www.bma.org.uk/endoflifecare">www.bma.org.uk/endoflifecare</a></p> <p>We suggest that further consideration is given to equality and inclusion issues, particularly for those for whom language may be a barrier – they need to understand the facts and other information in the same way as any other group; their fears and concerns need to be addressed in the same way as any other group. Particular attention should be given to the emotional and practical support for the elderly, for whom travel to and from appointments may be a real challenge.</p>
28	Sandwell and West Birmingham CCG	Patient information	<p>This isn't clear – except to say that information is important to patients and carers. Providing information about cancer prior to any diagnosis risks raising anxiety levels amongst patients and family members – what type of psychosocial support/counselling may be available to help this anxiety?</p>
29	RCGP		<p>The attribution implied here is interesting. I support the principle of giving information, but why only 'to encourage them to attend their appointment'? I can think of lots of other reasons to give information. Why not 'to enable them to participate fully in the process'?</p> <p>The reason is elaborated on p15 ('People with suspected cancer ...'). However the last phrase '... and reassure any doubts they may be having' is hardly justified. It will help, but the idea that giving such information will reassure any doubts is extraordinarily optimistic. (DJ)</p>

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29	RCGP		The list on p16 of the information required is sensible & helpful. It is often not possible to give information about how long it will take to have a diagnosis, and in some cases it is much longer than one would hope. However the main sticking point is item 2 ('How to get further information about the type of cancer'). At this point in the process where, according to the guidelines, the patient may have a probability of cancer as low as 3% they may not want to know any more about the type of cancer suspected. In my own case I tried to remember to ask them if they wanted to know more; some did and some didn't. (DJ)
29	RCGP		This statement aims to improve patient experience and if it also improves attendance at 2WW referral appointments will be good all round. (RM)
29	RCGP		It would be necessary to ensure all 2WW referrals coded and have code for this information being given and or way of recording at 2WW appt if patient had received this information prior to getting there. (RM)
30	NCRI-RCP-ACP		Our experts believe that patients who are referred to a specialist cancer service should also be signposted to support services for dealing with the psychological consequences of a suspected cancer diagnosis, and that this should be covered within the quality standard. Our experts were unaware whether this is addressed by other NICE cancer guidance apart from the 2004 guidance on supportive and palliative care for adults with cancer, which is to be updated.
32	Department of Health		This is relevant to all referrals, i.e. for the ones for direct access to tests as well as the ones on the two week wait suspected cancer pathway. Developing the 28 day standard will mean they have to be able to collect data about the direct access to tests
34	British Association of Dermatologists		In its current form, the relevant statement to skin cancer is mainly statement 3 - it's very generic and reasonably covers the aim to encourage patients referred to attend.

36	MDS UK Patient Support Group		<p>Q1: The quality statement 3 does not accurately reflect the key areas for quality improvement. This quality standard suggests that the full responsibility for the movement of patients along the cancer care pathways lies primarily with cancer patients. Patient information should be the integral part of all three important stages in the patient care (i.e. symptom suspicion and recognition, early referral and timely treatment) and not the quality standard on its own.</p> <p>Q4: The specific cancer population diagnosed with Myelodysplastic Syndrome has been completely unrecognised and left out of the original NG12 guidelines.</p> <p>Patients with a suspected blood disorder do not generally postpone or miss appointments to a haematologists. A more frequent scenario is that patients require several repeated GP appointments (and/or suffer numerous long-term infections) before a referral to a haematologist is finally made.</p> <p>40% of patients with anaemia are labelled with “unexplained anaemia”, without further investigations, let alone a referral to a haematologist. These are mostly older patients where anaemia is assumed to be a normal symptom of old age. Many MDS cases are part of this group of undiagnosed patients.</p> <p>A further group of older patients may get “diagnosed” with MDS by the GP (without a biopsy) and put on some form of supportive care/transfusions, without ever being referred to a haematologist. This is due to a lack of GP training regarding the exact nature of the MDS disease, and lack of up to date information about effective drug treatments for this disease. Great progress has been made in the area of MDS in the last 5 years – information that absolutely needs to be passed on to GP’s.</p> <p>Effective and appropriate treatment could keep these elderly patients leading active and independent lives for longer, instead of requiring more intense and costly care.</p> <p>The group of patients being currently and chronically overlooked are usually older people attending GP surgeries by themselves, or with their elderly spouse. This particular population does not tend to ask many questions and will follow all GP advice, information and instructions – when these are given to them.</p> <p>The vast majority of calls to MDS support groups comes from adult children of older patients who are not offered appropriate care, or referred at a late stage of the disease.</p>
37	Cancer Research UK		is a helpful suggestion, and we recommend using the leaflet that Cancer Research UK have recently developed.

37	Cancer Research UK		<p>Clear communication NICE Quality Standard could reference the Cancer Research UK leaflet (if evaluation shows it to be effective) as an exemplar of the information that could be provided, and utilise the NICE Field Team to ensure it is used.</p> <p>Clear communication with the patient is partially addressed by statement 3 and it is clear that pre-diagnosis is a time of uncertainty and heightened anxiety for patients. We agree that patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals, so the reason for referral and further information about next steps in the process should be clearly communicated to the patient.</p> <p>Although the quality standard does not specify what information should be provided, Cancer Research UK has recently produced a leaflet (<a href="#">‘Your Urgent Referral Explained’</a>) and online information<sup>10</sup>. The leaflet reinforces the importance of attending referral appointments and lays out the process step by step, including tips on how to prepare for appointments and getting results. For some patients, their symptom will not have aroused a suspicion of cancer and therefore managing communication to introduce the possibility of cancer sensitively but clearly is important.</p> <p>This leaflet adheres to the guidelines of the Information Standard and has been tested and reviewed by:</p> <ul style="list-style-type: none"> <li>▪ Focus group comprising participants with no experience of being referred for cancer tests</li> <li>▪ Cancer Research UK’s ‘sounding board’, comprised of people who are living with and beyond cancer</li> <li>▪ A lay reviewer and a GP reviewer</li> </ul> <p>Cancer Research UK has had a positive response to the leaflet and are continuing to evaluate. For example, Merseyside and Cheshire Clinical Network have requested an electronic version of the leaflet to include in their ‘Choose and Book’ appointment system (for GPs to print and give to patients) and printed leaflets to be distributed in hospital appointment letters. We have an opportunity to test this with CCGs in the region in 2016 and we would be happy to share further evaluation as it progresses.</p>
37	Cancer Research UK		<p>The Cancer Patient Experience Survey could be used to ask whether individuals were given information to encourage them to attend their diagnostic tests, and how satisfied they were with this - although this would only apply to those who went on to have a cancer diagnosis.</p>

<sup>10</sup> See <http://www.cancerresearchuk.org/about-cancer/cancer-symptoms/what-is-an-urgent-referral> and [http://publications.cancerresearchuk.org/publicationformat/formatcard/Your\\_Urgent\\_Referral\\_Explained.html](http://publications.cancerresearchuk.org/publicationformat/formatcard/Your_Urgent_Referral_Explained.html)

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4	Aintree Hospitals NHS Foundation Trust		<p>Not all patients are aware that they have been referred on a cancer pathway, on occasions the patients have been unavailable to attend an appointment as they are on holiday or when they have not attended on numerous occasions and the cancer team ring them and explain the importance of attending for appointment they are not aware the GP has sent them on a suspected cancer pathway.</p> <p>From a personal experience 2 family members who have been referred in were not aware they were being referred in a suspected cancer.</p>
5	Association of Breast Surgery		<p>The ABS supports information being given to people being referred with suspected breast cancer not only about the clinic process but also about the importance of attending any appointment because suspected cancer means just that and it is important to undergo any investigations promptly.</p>
7	British Thoracic Society		<p>In relation to information to encourage patients to attend a 2 week wait referral - this should be supported. However measuring this will be difficult and is best done in primary care, possibly via QOF.</p>
7	British Thoracic Society		<p>With regards to the information given in primary care this is quite an important area, of course however it goes beyond primary care and may also be important in secondary care where patients may be referred to MDTs with perhaps minimal information being provided. E.g. a person presents with an apparent pneumonia and a team then wonder if they may have an underlying cancer and we would refer them to the cancer MDT but will not always tell the patient that this has happened. Tightening up this communication is important though of course collecting the dataset to highlight this is really very difficult and the quality standard is very much directed to what happens in primary care.</p>
2	OPAAL UK	P14 – on the role of information	<p>Older people affected by cancer tell us that once cancer is suspected information which says most people who are referred do not have cancer does not alleviate their fears about their appointment to discuss results. Giving people information without access to emotional support is not an indicator of quality. OPAAL UK together with 13 project partners is delivering a cancer, older people and advocacy project, which sees older people affected by cancer supporting their peers from investigation and diagnosis and beyond. The older people who access our services tell us that having someone who has had experience of cancer by their side is invaluable. This type of support is an example of a low cost high quality intervention that indicates quality in care and support (for further information see <a href="http://www.opaalcopa.org.uk">www.opaalcopa.org.uk</a>)</p>
2	OPAAL UK	P5 role of family carers	<p>Comment about role of family/carers, OPAAL agrees strongly family members and carers must be involved where appropriate, we suggest this is expanded to include the role advocacy can play in supporting carers, as well as those with suspected cancer in supporting shared decision making and ensuring carers understand investigation, treatment and care options.</p>

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20	NHS England		We are not in a position to suggest specific groups that are not being referred appropriately. A thorough review of the data would be required. There is a risk in doing this analysis, in that 'direct access' tests are not two week wait referrals and would therefore not be captured in the current data. Much of the NICE guidance now suggests significant management of the pathway in primary care. Reviewing referral rates may therefore not give a very accurate picture of cancer investigation urgency.
25	British Medical Association	Question 4	Some variation in referral rates are inevitable as all practices have particular individual characteristics of their practice populations, with cancer incidence and hence referral rates influenced greatly by socioeconomic factors. Clearly the challenge for the clinician is to produce appropriate referrals with a 'sweet spot' where referral practices result in the maximum numbers of cancers detected at a curable stage, whilst not overloading services or subjecting those with low risks to harmful investigations.
1	University Hospitals Bristol NHS Foundation Trust		Teenagers and young adults with cancer – we have an ACE project at UH Bristol at present looking at that. Some ethnic/religious groups may be less willing for referral – for example some of the cultural groups in Bristol are less likely to attend if the word 'cancer' is mentioned which is a challenge for our GPs and us. People with mental health problems and learning disabilities generally have poorer access to healthcare for other conditions and are often harder to get through cancer pathways. And the whole 'vague symptoms' group aka non-site specific symptoms (e.g. weight loss) that are newly covered by the latest guidance, but most acute Trusts don't have specific services in place for and where poorer experience is more likely e.g. repeat attendances, being passed around between departments, less clearly defined pathways. I wouldn't say they are not being referred appropriately, as I don't have access to make that decision, but I think these are groups in the population who would benefit from a standard to help improve access for them.

19	Teenage Cancer Trust	Question 4:	<p>We would reiterate the comments made in our submission to the topic engagement, and support the submissions at that stage from the RCPCH, The Brain Tumour Charity and Breast Cancer Now, which all highlight the challenges that young people face in securing a referral for suspected cancer.</p> <p>Young people are likely to present at GPs multiple times with common cancer symptoms<sup>11</sup>, yet are more likely than older patients to have to visit their GP four or more times before being referred<sup>12</sup>. They are also more likely than adults to eventually be diagnosed at A&amp;E, with 37% being diagnosed through this route compared to 13% of 25-49 year olds<sup>13</sup>. Of that 37%, more than a quarter had previously been to see their GP with cancer symptoms but had not been referred to a specialist. This high rate of emergency presentation was highlighted in the Independent Cancer Taskforce's new cancer strategy for England<sup>14</sup>.</p> <p>Delays in primary care can impact on how young people cope with their diagnosis and treatment, and how they readjust to life afterwards<sup>15</sup>. Later diagnosis can lead to tumour progression, the need for more intensive treatment, raised anxiety and distrust of the medical profession<sup>16</sup>.</p> <p>Young people are less likely to recognise many common signs of cancer than older adults, even when prompted<sup>17</sup>. This highlights the importance of robust referral guidance for GPs when faced with a young person presenting with unexplained and persisted symptoms. Training for GPs in recognising the signs of cancer in young people, and in communicating with young people who attend their services, can help improve the experience of young people with cancer within primary care</p>
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<sup>11</sup> Teenage Cancer Trust (2011), Find Your Sense of Tumour conference survey

<sup>12</sup> Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey

<sup>13</sup> Teenage Cancer Trust (2013), Improving Diagnosis Report

<sup>14</sup> Independent Cancer Taskforce (2015), Achieving world-class cancer outcomes: a strategy for England 2015-2020

<sup>15</sup> Gibson et al (2013), Young people describe their prediagnosis cancer experience. *Psycho-Oncology* 10.1002

<sup>16</sup> Professor Tim Eden (2010), Teenage and Young Adult Cancer, *Oncology News*

<sup>17</sup> Public Health Agency (2014), Baseline Survey of Northern Ireland Public Awareness of Cancer Signs and Symptoms



22	Teenagers and Young Adults with Cancer (TYAC)	Question 4	<p>TYAC believes that teenagers and young adults could be referred in a more timely manner and have the potential to take longer to diagnosis. This group (13-24 year olds) would make a clearly defined group on which a specific quality statement could be made. TYAC, the TYA CRG and charities such as the Teenage Cancer Trust would welcome the opportunity to help with this quality statement.</p> <p>Young people are likely to present at GPs multiple times with common cancer symptoms<sup>18</sup>, yet are more likely than older patients to have to visit their GP four or more times before being referred<sup>19</sup>. They are also more likely than adults to eventually be diagnosed at A&amp;E, with 37% being diagnosed through this route compared to 13% of 25-49 year olds<sup>20</sup>. Of that 37%, more than a quarter had previously been to see their GP with cancer symptoms but had not been referred to a specialist. This high rate of emergency presentation was highlighted in the Independent Cancer Taskforce's new cancer strategy for England<sup>21</sup>.</p> <p>In addition, while two thirds of young people with cancer visit their GP with at least one of the most common cancer symptoms, one in four visit their GP four times or more before being referred<sup>22</sup>.</p> <p>Delays in primary care can impact on how young people cope with their diagnosis and treatment, and how they readjust to life afterwards<sup>23</sup>. Later diagnosis can lead to tumour progression, the need for more intensive treatment, raised anxiety and distrust of the medical profession<sup>24</sup>.</p> <p>Young people are less likely to recognise many common signs of cancer than older adults, even when prompted<sup>25</sup>. This highlights the importance of robust referral guidance for GPs when faced with a young person presenting with unexplained and persisted symptoms. Training for GPs in recognising the signs of cancer in young people, and in communicating with young people who attend their services, can help improve the experience of young people with cancer within primary care.</p> <p>We also believe that there is a real role in educating young people about the signs and symptoms of cancer so that young people can be proactive about presenting to their GP and ensuring that a potential diagnosis is not overlooked. There are existing programmes where this is happening in schools and universities but there is scope for this to be expanded.</p>
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<sup>18</sup> Teenage Cancer Trust (2011), Find Your Sense of Tumour conference survey

<sup>19</sup> Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey

<sup>20</sup> Teenage Cancer Trust (2013), Improving Diagnosis Report

<sup>21</sup> Independent Cancer Taskforce (2015), Achieving world-class cancer outcomes: a strategy for England 2015-2020

<sup>22</sup> Teenage Cancer Trust (2013), Improving Diagnosis Report

<sup>23</sup> Gibson et al (2013), Young people describe their prediagnosis cancer experience. Psycho-Oncology 10.1002

24	Association of British Neurologists	Question 4	<p>There are variations in referral rates for suspected cancer between general practices. Can you suggest which specific groups are not being referred appropriately in order to help define a specific population on which a quality statement can be written?</p> <p>Patients whose GPs do not have direct access to the appropriate investigation may be disadvantaged.</p> <p>Suspected cancer: recognition and referral (2015) NICE guideline NG12 currently advises primary care referrers on who and how to refer re suspected cancer. This suspected cancer quality standard in the attempt to improve time to cancer diagnosis and cancer-related morbidity and mortality may seek to address that the recommended pathways/services are available to the primary care referrer and if not consider does this contribute to diagnosis delay.</p> <p>For example NICE 2015 guidance for suspected brain tumours recommends that direct access urgent MRI brain be performed. Many GPs do not have access to this service and therefore will need to refer to secondary care with possible delay in diagnosis.</p>
25	British Medical Association	Question 4	<p>Men in general are an at risk population because of their general tendency not to seek advice. Other groups include the elderly, the socially disadvantaged particularly the homeless, those with mental health problems or learning difficulties.</p>
28	Sandwell and West Birmingham CCG	Question 4	<p>Specific groups missed – it is commonly acknowledged that many men visit the chemist or supermarket pharmacy for antacids/indigestion mixture rather than visiting their doctor and this is how many develop oesophageal cancer. Is there a role here for community pharmacists to play in suggesting referrals to primary care or even for secondary care? Again, caught early, more treatment options exist and better outcomes. Awareness amongst men in particular and smokers of the prevalence of throat/oesophageal cancers needs raising.</p>
29	RCGP	Question 4	<p>There are variations in referral rates for suspected cancer between general practices. Can you suggest which specific groups are not being referred appropriately in order to help define a specific population on which a quality statement can be written?</p> <p>Perhaps younger women with blood in urine as this is often put down to urinary tract infection for too long delaying diagnosis. (<a href="http://www.nhs.uk/news/2013/06June/Pages/Female-kidney-and-bladder-cancers-diagnosed-late.aspx">http://www.nhs.uk/news/2013/06June/Pages/Female-kidney-and-bladder-cancers-diagnosed-late.aspx</a>). (RM)</p>
32	Department of Health	Page 5 – Question 4	<p>Analysis by PHE provides insight into groups that could benefit from improved referral. However, it is difficult to tell characteristics of those referred late by GPs vs those who present late to their GP?  <a href="http://www.ncin.org.uk/publications/routes_to_diagnosis">http://www.ncin.org.uk/publications/routes_to_diagnosis</a></p>

<sup>24</sup> Professor Tim Eden (2010), Teenage and Young Adult Cancer, Oncology News

<sup>25</sup> Public Health Agency (2014), Baseline Survey of Northern Ireland Public Awareness of Cancer Signs and Symptoms

33	Prostate Cancer UK	<p>As in our original submission we would want to ensure that men get improved information and support in primary care. Men also need additional support in relation to deciding whether to have a PSA test. The PSA test can be unreliable due to poor sensitivity and specificity. Men require substantial information and support from primary care professionals to enable them to make informed choices (1).</p> <p>From studies we have conducted with both men (2) and GPs (3) we know that improved information and support would be welcomed.</p> <p>(1) Evans R, Joseph-Williams N, Edwards A, Newcombe RG, Wright P, Kinnersley P, et al. Supporting informed decision making for prostate specific antigen (PSA) testing on the web: an online randomized controlled trial. J Med Internet Res. 2010;12(3):e27.</p> <p>(2) Prostate Cancer UK. Men's Views and Experience of being Referred for Suspected Prostate Cancer. Figures from Prostate Cancer UK online survey. Total sample size was 591 men living in the UK. Fieldwork was undertaken between October 2014 and November 2014. 2014.</p> <p>(3) Kanter Health. Figures from a survey of 500 GPs in the UK conducted by Kanter Health on behalf of Prostate Cancer UK in January 2014. 2014.</p>
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37	Cancer Research UK	<p>There are variations in referral rates for suspected cancer between general practices. Can you suggest which specific groups are not being referred appropriately in order to help define a specific population on which a quality statement can be written?</p>	<p>NICE need to ensure that Quality Standards are sufficiently strong to encourage change, otherwise further quality statements will be obsolete.</p> <p>Evidence suggests there are several groups where variation has been identified. Data on the primary care diagnostic interval, or further interrogation of Routes to Diagnosis/emergency presentation data, could offer further insights on who may benefit from a QS. Using a measure from the Cancer Patient Experience Survey, there is wide variation between cancer types in the proportion of patients who had visited their GP three or more times before hospital referral. People who are more likely to have had three or more pre-referral consultations include:</p> <ul style="list-style-type: none"> <li>• Patients who have a subsequent diagnosis of multiple myeloma, pancreatic, stomach or lung</li> <li>• Younger patients (aged 16 – 24 years)</li> <li>• Those from ethnic minorities</li> <li>• Women<sup>26</sup></li> </ul> <p>NICE could therefore consider a quality statement relating to people from these demographic groups.</p> <p>It may also be worthwhile considering the investigation of non-specific but concerning symptoms, or those relating to organs which cannot be palpated or inspected. This could include use of new models of multispecialty diagnostic services which ‘can help to integrate diagnostic assessment processes and minimise prolonged investigation intervals or the risk of referral to the “wrong” specialty’<sup>27</sup>. The Accelerate, Coordinate and Evaluate programme (ACE) Wave 2 of the programme is focused on piloting a new pathway for patients with non-specific or vague symptoms of cancer. It will be working with six pilot sites across the country testing how a ‘Multi-Disciplinary Diagnostic Centre’ approach might work in the NHS over the next three years.</p> <p>This link with innovative diagnostic models should be explored as a potential avenue for further quality standard work.</p>
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<sup>26</sup> Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England – Lyratzopoulos et al 2012, <http://www.sciencedirect.com/science/article/pii/S1470204512700414>

<sup>27</sup> Lyratzopoulos G, Wardle J and G Rubin, Rethinking diagnostic delay in cancer: how difficult is the diagnosis?, BMJ 2014. <http://www.bmj.com/content/349/bmj.g7400.long>

27	Brain Tumour Research	Question 4	<p>More needs to be done to raise awareness, particularly in primary care settings, of the symptoms of rarer cancers in order to increase the speed, effectiveness and accuracy of referrals. As a charity and patient group representative, we hear time and time again of delays in identifying and referring treatment for brain tumours. Often this is due to the failure of GPs and other healthcare professionals to correctly recognise the symptoms of this disease. Brain tumours manifest themselves in various ways in different patients, which means that effective education must be undertaken by primary care staff (and healthcare staff more widely) in order to understand and recognise the variety of symptoms.</p> <p>As with other cancers, fast and accurate referral is crucial to maximise the chance of survival of a brain tumour patient. More must be done to train and educate GPs on rarer cancers and ensure that this is standardised across the country. This would also help to achieve Domain 4 of the NHS Outcomes Framework 2015-16, ensuring that people have a positive experience of care.</p>
24	Association of British Neurologists		<p>Though we understand the need to highlight recommendations regarding site-specific cancers our understanding of the focus of this quality standard was to provide standards applicable to all cancer groups.</p> <p>Rather than giving two statements focused on a site-specific cancer we would welcome a statement within the quality standard that recognises the need for primary care to be aware of the NICE guideline NG12, which currently advises primary care referrers on who and how to refer re suspected cancer, which also stresses that primary care have direct access to the appropriate investigation listed in this guideline.</p> <p>At present there is no uniform direct access to diagnostic services available to primary care. Patients in certain geographic areas may be disadvantaged, due to the lack of this availability, necessitating referral to secondary care and therefore a potential delay in diagnosis.</p>
27	Brain Tumour Research	Question 2	<p>Funding and prioritisation should be given to collecting data that support the improvement of the care pathway for those with suspected cancer. Brain Tumour Research would like to stress the importance of prioritising data collection of rarer cancers.</p> <p>Collecting data for rarer cancers can be challenging due to a number of factors, not least given the limited pool of those involved in clinical trials. It is vital, however, to make a concerted effort to include this patient population in the collection of data in order to ensure full and effective adherence to the NHS Outcomes Framework 2015-16, and an improvement in outcomes for all those with cancer.</p>
28	Sandwell and West Birmingham CCG	Introduction	<p>Unsure why lung cancer hasn't been specified given the prevalence, high mortality and evidence that those caught earlier in the pathway (ideally through primary care rather than A&amp;E) do better in performance/treatment options.</p>

37	Cancer Research UK	General	<p>We welcome the opportunity to respond to this consultation. The NICE guidelines on recognition and referral of suspected cancer (NG12) provide an opportunity to improve cancer outcomes. By lowering the positive predictive value (PPV) to 3% or below, these guidelines make a welcome contribution to:</p> <ul style="list-style-type: none"> <li>• Earlier diagnosis of cancer, leading to increased survival</li> <li>• A reduction in cancers diagnosed via an emergency route</li> <li>• Optimised diagnostic processes</li> <li>• More appropriate referrals to secondary care for suspected cancer.</li> </ul> <p>As noted in the cancer strategy<sup>28</sup>, implementation of the guidelines require more diagnostic capacity to meet the increased demand which will arise.</p> <p>Summary</p> <p>Further areas beyond the proposed quality statements should be considered for quality improvement. These include:</p> <ul style="list-style-type: none"> <li>Growing diagnostic capacity: planning, commissioning and staffing</li> <li>Eliminating unwarranted variation in referrals</li> <li>GP access to secondary care expertise (improving the primary/secondary care interface)</li> <li>Application and communication of the guidelines</li> <li>Timeliness of investigation and reporting</li> </ul>
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<sup>28</sup> Achieving World Class Cancer Outcomes: a Strategy for England, 2015 – 2020 (2015) Independent Cancer Taskforce

<p>37</p>	<p>Cancer Research UK</p>	<p>Does this draft quality standard accurately reflect the key areas for quality improvement ?</p>	<p><b>2.</b> We have identified several key areas for quality improvement, not all of which are covered in the draft quality standard. These areas have also been reiterated by primary and secondary care clinicians at a recent roundtable event (held in London, 14th January 2016) who agreed that more could be achieved through a focus on:</p> <ul style="list-style-type: none"> <li>Growing diagnostic capacity: planning, commissioning and staffing</li> <li>Eliminating unwarranted variation in referrals</li> <li>Ensuring universal direct access to key investigative tests for suspected cancer – blood tests, chest x-ray, ultrasound, MRI, CT and endoscopy</li> <li>GP access to secondary care expertise (improving the primary/secondary care interface)</li> <li>Clear communication with patient</li> <li>Application and communication of the guidelines</li> <li>Timeliness of investigation and reporting</li> </ul> <p>Diagnostic Capacity Underpinning any attempts at quality improvement for cancer referral must be diagnostic capacity. Given how significant broader access to diagnostics is in the guidance, the importance of these services being commissioned and sufficiently staffed to support implementation cannot be overstated. Adequate diagnostic capacity is essential for the implementation of the guidelines and any quality improvement. For example, our report examining the future demand for endoscopy (including the impact of NG12) has highlighted that more than 250,000 additional endoscopy procedures a year will be needed by 2020 – representing a 44% increase on current activity.<sup>29</sup></p> <p>Timeliness of investigation and reporting The Quality Standard should reflect the need for timeliness to include reporting results back to patients, and be updated in line with findings from the NHS England ‘Find Out Fast’ pilots.</p> <p>The cancer strategy outlined an ambition for NHS England to develop ‘a new metric for earlier diagnosis measurable at CCG level. Patients referred for testing by a GP, because of symptoms and/or clinical judgement, should either be definitively diagnosed with cancer or cancer excluded and these results should be communicated to the patient within four weeks’.<sup>30</sup> This ‘Find Out Fast’ metric is currently being developed and will be piloted with a ‘test and learn’ approach in 2016 in a small number of health economies in England.</p>
<p><sup>29</sup></p>	<p>Scoping the Future (2015) Cancer Research UK and 2016</p>	<p>GP Access to Secondary Care Expertise</p>	<p>GP Access to Secondary Care Expertise International comparisons of different healthcare systems have suggested that access to secondary care could be a factor which influences the speed of cancer diagnosis<sup>31</sup>. It has been suggested that GPs in England need better access to the advice of secondary care colleagues to assist with making difficult referral decisions. The cancer strategy calls on CCGs to ‘consider how they can facilitate more regular discussions between primary and secondary care, to optimise referral pathways’<sup>32</sup></p> <p>Efforts to improve the primary and secondary care interface should be considered as part of the quality standard, and could include improving clinical pathways through the developing cancer alliances</p>

17	Faculty of General Dental Practice (UK)		The development of an official resource for information for service providers and healthcare professionals, (including materials and information for sharing with patients) would be logical, assuming the ultimate aim is that the standards in the quality statement are to be universally met. An online cancer portal would be very helpful for service providers and healthcare professionals, including dentists.
18	British Dental Association		The development of an online cancer portal would be very helpful for dental practitioners and should be included in the quality statement.
18	British Dental Association	measures	Dentists currently document referrals for suspected oral cancer in their clinical records, and it should be straightforward for them to note also when information is provided to the patient about the importance of attending a specialist appointment. A means of collecting these data without adding to dentists' administrative burden would be required where paper record systems are still in place.
31	Royal College of Nursing		There are no further comments to make on this document on behalf of the Royal College of Nursing
32	Department of Health	Page 19	National Cancer Strategy: impact assessment now superseded by Achieving World-Class Cancer Outcomes published at <a href="http://www.cancerresearchuk.org/about-us/cancer-taskforce">http://www.cancerresearchuk.org/about-us/cancer-taskforce</a>
32	Department of Health	Page 19	Improving Outcomes: A Strategy for Cancer superseded by Achieving World-Class Outcomes <a href="http://www.cancerresearchuk.org/about-us/cancer-taskforce">http://www.cancerresearchuk.org/about-us/cancer-taskforce</a>
32	Department of Health	Page 19	The national cancer strategy – superseded by Achieving World-Class Cancer Outcomes <a href="http://www.cancerresearchuk.org/about-us/cancer-taskforce">http://www.cancerresearchuk.org/about-us/cancer-taskforce</a>
6	British Association of Oral and Maxillofacial Surgery (BAOMS)	1.82	We are concerned that leaving a suspicious oral ulcer 3 weeks before referral to a specialist is too long. What is the evidence to support 3 weeks? Would 2 weeks be a better time frame?
6	British Association of Oral and Maxillofacial Surgery (BAOMS)	1.83	We feel that an appointment for assessment by a dentist for possible oral cancer is inappropriate. A large proportion of the population do not have a dentist or will not be able to get an appointment with a dentist within 2 weeks. This introduces an unnecessary delay, and means that patients may wait up to a month to see a specialist, which could significantly affect their prognosis.

<sup>30</sup> Achieving World Class Cancer Outcomes: a Strategy for England, 2015 – 2020 (2015) Independent Cancer Taskforce

<sup>31</sup> Rose, PW et al. Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. 2015, BMJ

Open

<sup>32</sup> Achieving World Class Cancer Outcomes: a Strategy for England, 2015 – 2020 (2015) Independent Cancer Taskforce



7	British Thoracic Society	General	<p>There are large gaps in the quality standard especially around lung cancer. I am aware of the correspondence between Dr Baldwin, Chair of the Lung Cancer Clinical Reference Group and NICE when the guideline CG27 was being developed. Hence it is very surprising that this is not mentioned in the current quality standard.</p> <p>Lung cancer is one of the most common cancers with the worse prognosis. Survival can be improved by curative interventions if they occur at an early stage. For lung cancer it is clear early diagnosis is essential.</p> <p>It is therefore with considerable disappointment that BTS notes that the clinical guidelines for suspected cancer fails to mention lung cancer. We would be grateful if you could highlight in which particular forum you anticipate a quality standard for early diagnosis of lung cancer to appear.</p>
8	Lancashire Care NHS Foundation Trust	General	<p>I have noticed that recent quality standards give a much better definition of who is expected to meet a quality standard e.g. Healthcare professionals (GPs). This makes it a great deal easier to try and work out / triage who the standard is for (ref Susan Michie), so please carry on with these definitions, they're helpful.</p>

***Registered stakeholders who submitted comments at consultation***

- Aintree Hospitals NHS Foundation Trust
- Association of Breast Surgery
- Association of British Neurologists
- Association of Child Psychotherapists
- Association of Clinical Pathologists
- Bowel Cancer UK
- Brain Tumour Research
- British Association of Dermatologists
- British Association of Oral and Maxillofacial Surgery (BAOMS)
- British Dental Association

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- British Medical Association
- British Society of Gastroenterology (BSG)
- British Thoracic Society
- Cancer Research UK
- Department of Health
- Faculty of General Dental Practice (UK)
- Lancashire Care NHS Foundation Trust
- Manchester Cancer
- MDS UK Patient Support Group (MSD foundation)
- National Cancer Research Institute (NCRI)
- NHS England
- Norfolk and Norwich University Hospitals NHS Foundation Trust
- Oesophageal Cancer Westminster Campaign
- Oesophageal Patients' Association
- OPAAL UK
- Prostate Cancer UK
- Royal College of General Practitioners in Wales (RCGP)
- Royal College of Nursing
- Royal College of Obstetricians and Gynaecologists (RCOG)

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- Royal College of Paediatrics and Child Health
- Royal College of Physicians and Surgeons of Glasgow (RCPSG)
- Sandwell and West Birmingham CCG
- South Sefton CCG
- Teenage Cancer Trust
- Teenagers and Young Adults with Cancer (TYAC)
- The Brain Tumour Charity
- University Hospitals Bristol NHS Foundation Trust
- Vale Royal CCG