NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Suspected cancer

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 03 November 2015

Contents

1 Introduction

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

1.1 Structure

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

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

1.2 Development source

The key development source referenced in this briefing paper is:

- Suspected cancer: recognition and referral (2015) NICE guideline NG12

2 Overview[1]

2.1 Focus of quality standard

This quality standard will cover recognition and referral of suspected cancer in children, young people and adults.

NICE guideline 12 on suspected cancer contains recommendations relevant to all people with suspected cancer and also cancer site specific recommendations. Responses received at engagement on the quality standard topic overview focussed on the areas for quality improvement that are common to all patients. Cancer site specific suggestions were used as examples of practice that could be applicable to wider populations. This paper therefore does not present areas for quality improvement specific to individual cancer sites.

2.2 Definition

Cancer[2] is a condition where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding tissue,

---

[1] Unless otherwise referenced, sections 2.2 to 2.4 are adapted from NICE guideline NG12 Suspected cancer: recognition and referral (2015).

[2] NHS Choices website: Cancer (Accessed October 2015)

including organs. There are over 200 different types of cancer, each with its own methods of diagnosis and treatment.

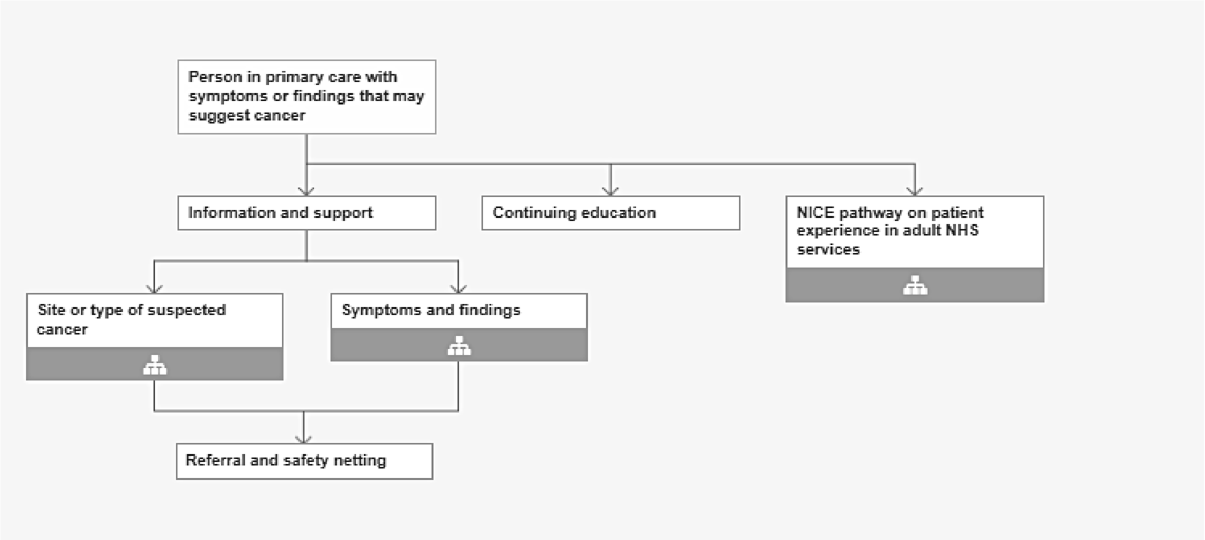
2.3 Incidence and prevalence

Cancer has an enormous impact, both in terms of the number of people affected by it and the individual impact it has on people with cancer and those close to them. More than 300,000 new cancers (excluding skin cancers) are diagnosed annually in the UK. Each of these cancer types has different presenting features, though they sometimes overlap. Approximately one‑third of the population will develop a cancer in their lifetime. There is considerable variation in referral and testing for possible cancer, which cannot be fully explained by variation in the population.

The identification of people with possible cancer usually happens in primary care, because the large majority of people first present to a primary care clinician. Therefore, evidence from primary care should inform the identification process and was used as the basis for this guideline.

2.4 Management

The typical pathway for investigation and detection of suspected cancer begins with a person presenting at primary care with symptoms or concerns. The NICE pathway for suspected cancer is outlined below:



Some investigations may be performed in primary care, such as blood tests like prostate specific antigen or CA125. Imaging investigations, such as chest X-rays, or ultrasound, are generally available directly via referral from GPs. Conversely, some investigations (such as colonoscopy or biopsy) are accessed only through secondary care and so require formal referral.

2.5 National Outcome Frameworks

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

Table 1 NHS Outcomes Framework 2015–16

Domain	**Overarching indicators and improvement areas**
1 Preventing people from dying prematurely	***Overarching indicators*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults ii Children and young people 1b Life expectancy at 75 i Males ii Females ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer* (PHOF 4.5) i One- and ii Five-year survival from all cancers iii One- and iv Five-year survival from breast, lung and colorectal cancer *v One- and vi Five-year survival from cancers diagnosed at stage 1 & 2** (PHOF 2.19)*
4 Ensuring that people have a positive experience of care	***Overarching indicator*** 4a Patient experience of primary care i GP services 4d Patient experience characterised as poor or worse i. Primary care ***Improvement areas*** **Improving access to primary care services** 4.4 Access to i GP services **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment across the health and social care system * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 Public health outcomes framework for England, 2013–2016

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.19 Cancer diagnosed at stage 1 and 2**(NHSOF 1.4) 2.20 Cancer screening coverage
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.3 Mortality rate from cause considered preventable **(NHSOF 1a) 4.5 Under 75 mortality rate from cancer*
Alignment across the health and social care system * Indicator is shared ** Indicator is complementary	

3 Summary of suggestions

3.1 Responses

In total 22 stakeholders responded to the 2-week engagement exercise 09/09/15 until 23/09/15.

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

Full details of all the suggestions provided are given in appendix 2 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Diagnosis • Early detection in primary care • Faster diagnosis • Diagnostic availability/access	AAH, ABN, CRUK, ELH, LC, PCUK, RCGP, RCPCH, SCM1, SCM2, SCR, TBTC, TCT
Active monitoring • Active monitoring	CRUK, SCM2, LC
Referral criteria • Fast-track referral from GP • Atypical presentation	TBTC, SCM1, LC, ELH, CRUK, BTS, BCN BCN, BAD, CRUK, CCLG, RCGP, RCP, UHBNFT
Information and support • Patient information and support	BCN, CCLG, CRUK, ELH, LC, PCUK, RCGP, RCP, UHBNFT
AAH, Action Against Heartburn ABS, Association of Breast Surgery ABN, Association of British Neurologists BCN, Breast Cancer Now BAD, British Association of Dermatologists BTS, British Thoracic Society CRUK, Cancer Research UK CCLG, Children’s Cancer and Leukaemia Group ELH, East Lancashire Healthcare LC, London Cancer NHSE, NHS England PCUK, Prostate Cancer UK RCGP, Royal College of General Practitioners RCN, Royal College of Nursing RCPCH, Royal College of Paediatrics and Child Health RCP, Royal College of Physicians SCM, Specialist Committee Member SCR, Society and College of Radiographers TCT, Teenage Cancer Trust TBTC, The Brain Tumour Charity UHBNFT, University Hospitals Bristol NHS Foundation Trust	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1304 studies were identified for QS topic. In addition, current practice examples were suggested by stakeholders at topic engagement (68).

Of these studies, 47 were assessed as having potential relevance to this topic and the suggested areas for quality improvement identified by stakeholders (see appendix 2). A summary of relevant studies is included in the current practice sections for each suggested area of improvement.

4 Suggested improvement areas

4.1 Diagnosis

4.1.1 Summary of suggestions

Early detection in primary care

Stakeholders highlighted the need for improvement in the early recognition of cancer and the key role primary care can play in this. They said that early detection can improve survival and quality of life for all cancers. There were comments that stated there may be some variation across the country which needs to be addressed.

In addition the better use of information about risk to inform early detection was raised by stakeholders.

Time to diagnosis

Stakeholders highlighted that the time taken to diagnose with cancer is critical in surviving cancer. It was also noted that there are a number of parts of the pathway even within early recognition and referral where delays can and do occur. Direct access to specific tests could lead to faster diagnosis.

A stakeholder highlighted that the results and outcomes of urgent tests need to be reported in a timely fashion to ensure that the overall diagnoses is completed and resolved and ensures there are no delays along the way to endanger patients.

Diagnostic availability and access

Stakeholders highlighted that there may be issues with availability of and access to some of diagnostic procedures. It was suggested that more tests should be available via direct access schemes (depending on the setup of services in a geographical area).

4.1.2 Selected recommendations from development source

The recommendations below have been provisionally selected from the development source to support potential statement development.

Early detection in primary care

NICE NG12 recommendation 1.16.2

Discussion with a specialist (for example, by telephone or email) should be considered if there is uncertainty about the interpretation of symptoms and signs, and whether a referral is needed. This may also enable the primary healthcare professional to communicate their concerns and a sense of urgency to secondary healthcare professionals when symptoms are not classical.

NICE NG12 recommendation 1.16.3

Put in place local arrangements to ensure that letters about non-urgent referrals are assessed by the specialist, so that the person can be seen more urgently if necessary.

NICE NG12 recommendation 1.16.8

Once the decision to refer has been made, make sure that the referral is made within 1 working day.

Time to diagnosis

NG12 contains site specific cancer recommendations on direct access to tests. For example, recommendation 1.2.1:

Offer urgent direct access upper gastrointestinal endoscopy (to be performed within 2 weeks) to assess for oesophageal cancer in people:

- with dysphagia or
- aged 55 and over with weight loss and any of the following:
- upper abdominal pain
- reflux
- dyspepsia. [new 2015]

NICE NG12 recommendation 1.15.1

Ensure that the results of investigations are reviewed and acted upon appropriately, with the healthcare professional who ordered the investigation taking or explicitly passing on responsibility for this. Be aware of the possibility of false‑negative results for chest X‑rays and tests for occult blood in faeces.

Diagnostic availability/access

NICE NG12 recommendation 1.16.2

Discussion with a specialist (for example, by telephone or email) should be considered if there is uncertainty about the interpretation of symptoms and signs, and whether a referral is needed. This may also enable the primary healthcare professional to communicate their concerns and a sense of urgency to secondary healthcare professionals when symptoms are not classical.

NICE NG12 recommendation 1.16.3

Put in place local arrangements to ensure that letters about non-urgent referrals are assessed by the specialist, so that the person can be seen more urgently if necessary.

NICE NG12 recommendation 1.16.4

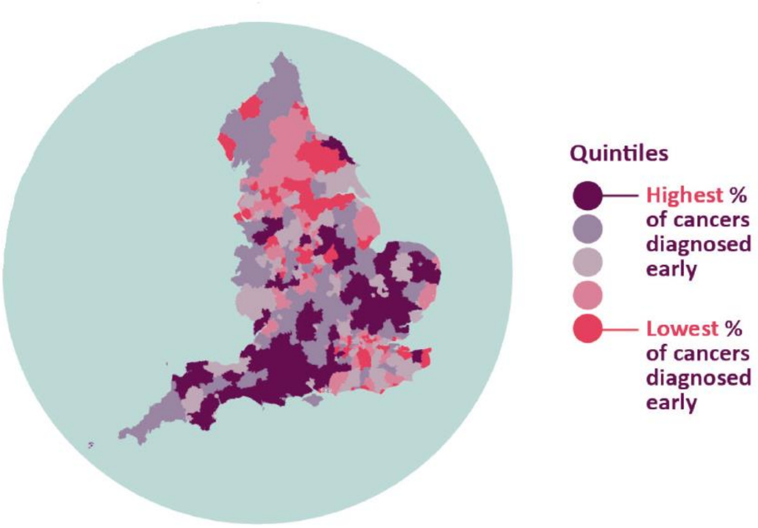
Put in place local arrangements to ensure that there is a maximum waiting period for non-urgent referrals, in accordance with national targets and local arrangements.

4.1.3 Current UK practice

Factors that could contribute to delays in cancer diagnosis and poorer cancer outcomes include centralisation of services, free movement of patients between primary care providers, access to secondary care, and the existence of patient list systems.[3]

Cancer Research[4] cited work undertaken by Elliss-Brookes et al (2012) which states that only 27% of cancers are diagnosed via the urgent referral pathway. Variation in the stage at which cancers are diagnosed exists between geographic locations, ethnicities, genders and across socio-demographic factors. It is estimated that thousands of advanced stage diagnoses could be avoided each year if socio-demographic inequalities at stage of diagnosis were eliminated. The chart below shows variation by local authority:

Chart 1: Stage of diagnosis by local authority, 2012



---

[3] Brown S, Castelli M, Hunter D et al (2014) How might healthcare systems influence speed of cancer diagnosis: A narrative review *Social Science & Medicine* *Volume 116*
[4] Independent Cancer Taskforce, Achieving world-class cancer outcomes, A strategy for England 2015-2020

4.2 Active monitoring

4.2.1 Summary of suggestions

Active monitoring

Stakeholders highlighted that the process of active monitoring (safety netting) of people in primary care who have presented with symptoms is variable across the country and should be more consistent. It was also raised that the review of patients with low risk is important to ensure that diagnoses are not missed.

4.2.2 Selected recommendations from development source

The recommendations below have been provisionally selected from the development source to support potential statement development.

Active monitoring

NICE NG12 recommendation 1.15.2

Consider a review for people with any symptom that is associated with an increased risk of cancer, but who do not meet the criteria for referral or other investigative action. The review may be:

- planned within a time frame agreed with the person or
- patient‑initiated if new symptoms develop, the person continues to be concerned, or their symptoms recur, persist or worsen.

4.2.3 Current UK practice

No current practice has been identified specific to active monitoring and the provision of safety netting advice.

The Independent Cancer Taskforce strategy[5] recommended that processes need establishing in GP practices to ensure ‘safety netting’ of patients becomes regular practice.

---

[5] [5] Independent Cancer Taskforce, Achieving world-class cancer outcomes, A strategy for England 2015-2020

4.3 Referral criteria

4.3.1 Summary of suggestions

Fast track referral from GP

Stakeholders highlighted a number of site specific cancer areas where faster referrals mean the cancers can be diagnosed earlier and ensure the best outcomes for patients. Stakeholders also highlighted the importance to wellbeing that having a shorter time to either diagnosis or confirmation of not having cancer brings.

Atypical presentation

Stakeholders highlighted that suspicion of cancer should be acted upon regardless of age or symptom. For example stakeholders highlighted the need for improvement in recognition of symptoms in populations such as children and young people. A number of stakeholders noted that people outside of the expected age groups of some cancers means that they attend a GP's practice on more than one occasion. Additionally stakeholders stated that presentation at the GP without typical symptoms, such as no lump for breast cancer suspicion, should not in itself stop investigations

4.3.2 Selected recommendations from development source

The recommendations below have been provisionally selected from the development source to support potential statement development.

Fast track referral from GP

NG12 contains site specific cancer recommendations on direct access to tests. For example, recommendation 1.2.4:

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for pancreatic cancer if they are aged 40 and over and have jaundice.

Atypical presentation

<u>NICE NG12 research recommendation 2.1</u>

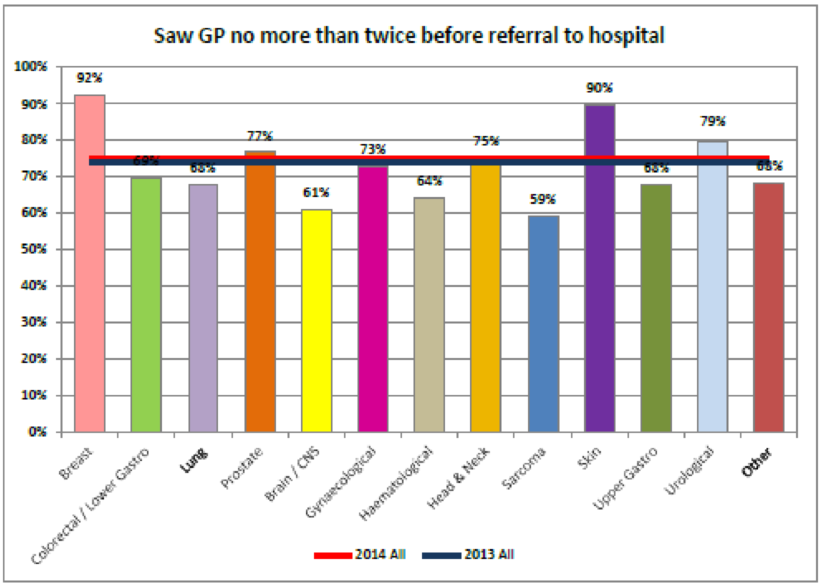
Longitudinal studies should be carried out to identify and quantify factors in adults that are associated with development of specific cancers at a younger age than the norm. They should be designed to inform age thresholds in clinical guidance. The primary outcome should be likelihood ratios and positive predictive values for cancer occurring in younger age groups

4.3.3 Current UK practice

Data published by the National Cancer Intelligence Network shows that the rate at which GPs refer patients for suspected cancer varies widely. In some cases, GPs refer more than 3 times as many patients as others[6].

The Cancer Patient Experience Survey 2014[7] shows variation in the proportion of patients who only saw their GP once or twice before being referred. Scores ranged from by cancer site from 59% (sarcoma) to 92% (breast). The chart below shows the figures according to cancer site.

Chart 2: Patients who saw their GP no more than twice before being referred



---

[6] Nigel Hawkes (2012) Urgent referrals for suspected cancer vary threefold among general practices. BMJ 2012;345;E5195

[7] NHS England, Cancer Patient Experience Survey 2014

4.4 Information and support

4.4.1 Summary of suggestions

Patient information and support

Stakeholders highlighted that ensuring the patients understand the need for attendance within the given timeframe is important. This is to ensure that patients do not further delay diagnosis by re-arranging appointments.

4.4.2 Selected recommendations from development source

The recommendations below have been provisionally selected from the development source to support potential statement development.

Patient information and support

NICE NG12 recommendation 1.14.1

Discuss with people with suspected cancer (and their carers as appropriate, taking account of the need for confidentiality) their preferences for being involved in decision‑making about referral options and further investigations including their potential risks and benefits.

NICE NG12 recommendation 1.14.2

When cancer is suspected in a child, discuss the referral decision and information to be given to the child with the parents or carers (and the child if appropriate).

NICE NG12 recommendation 1.14.3

Explain to people who are being referred with suspected cancer that they are being referred to a cancer service. Reassure them, as appropriate, that most people referred will not have a diagnosis of cancer, and discuss alternative diagnoses with them.

4.4.3 Current UK practice

There are publically available examples of information leaflets for patients to assist in ensuring their understanding[8].

---

[8] London Cancer, Patient information for urgent referrals

4.5 Additional areas

Summary of suggestions

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

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 03/11/15.

Online Cancer Portal

Stakeholders highlighted that an online cancer portal which is aligned with other systems along the pathway would enable the patient to progress through the pathway seamlessly. The portal could assist in choosing the appropriate referral pathway and provide reports along the way to CCG’s and commissioners.

GP training

Stakeholders suggested that regular primary care clinician training can assist with the identification of non-specific symptoms of disease presentation that could be cancer contribute towards the early detection of cancer.

Appendix 1: Glossary

Children From birth to 15 years.

Children and young people From birth to 24 years.

Consistent with The finding has characteristics that could be caused by many things, including cancer.

Direct access When a test is performed and primary care retain clinical responsibility throughout, including acting on the result.

Immediate An acute admission or referral occurring within a few hours, or even more quickly if necessary.

Non‑urgent The timescale generally used for a referral or investigation that is not considered very urgent or urgent.

Persistent The continuation of specified symptoms and/or signs beyond a period that would normally be associated with self‑limiting problems. The precise period will vary depending on the severity of symptoms and associated features, as assessed by the health professional.

Raises the suspicion of A mass or lesion that has an appearance or a feel that makes the healthcare professional believe cancer is a significant possibility.

Safety netting The active monitoring in primary care of people who have presented with symptoms. It has 2 separate aspects:

- timely review and action after investigations
- active monitoring of symptoms in people at low risk (but not no risk) of having cancer to see if their risk of cancer changes.

Suspected cancer pathway referral The patient is seen within the national target for cancer referrals (2 weeks at the time of publication of this guideline).

Unexplained Symptoms or signs that have not led to a diagnosis being made by the healthcare professional in primary care after initial assessment (including history, examination and any primary care investigations).

Urgent To happen/be performed within 2 weeks.

Very urgent To happen within 48 hours.

Young people Aged 16–24 years.

Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
1	4.1	Action Against Heartburn	Earlier diagnosis of oesophageal adenocarcinoma	5-year survival rate for oesophageal cancer is low at 15% but affects 8,300 patients diagnosed in UK annually. The UK incidence of oesophageal adenocarcinoma (OAC) is highest in the world. Outcomes are significantly better for patients diagnosed at earlier stages.	The incidence of OAC has increased eightfold in the last three decades to become the sixth most common cancer in the UK. Before the 1970s, 90% of oesophageal cancers were squamous; but now 70% are OAC. The reason for this epidemiological shift is an increase in gastro-oesophageal reflux disease (GORD) and its principal complication Barrett's Oesophagus, the only known precursor lesion for OAC.	Global Incidence of oesophageal cancer by histological sub-type in 2012 Melina Arnold et al Gut doi: 10.1136/gutjnl-2014-308124 http://gut.bmj.com/content/early/2014/09/16/gutjnl-2014-308124 Heartburn, Barrett's Oesophagus and cancer: implications for primary care Anthony Watson and John Galloway British Journal of General Practice March 2014 http://bjgp.org/content/64/620/120
2	4.1	Action Against Heartburn	Proposed Quality Standard	'Number of patients referred for endoscopy or specialist service with: • Unresolved persistent heartburn / dyspepsia, or • Previously diagnosed Barrett's Oesophagus between surveillance periods, or not subject to surveillance, or • At risk of dysplasia but not previously diagnosed with Barrett's	It is important to diagnose cancer from precursor conditions rather than rely on referral when the tumour has developed past the point when curative treatment has become impossible. The pragmatic cross-reference to unresolved persistent heartburn /	*No additional information provided by stakeholder.*

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Oesophagus (See QS96 Quality Standard on Management of Dyspepsia and GORD: Statement 5: Adults with persistent, unexplained dyspepsia or reflux symptoms have a discussion with their GP about referral to a specialist service)'	dyspepsia is from NICE Quality Standard 96 which has important cancer-related implications.	
3	4.1	Action Against Heartburn	Proposed Quality Standard	'Number of patients referred as above and then diagnosed with a) Barrett's Oesophagus b) Low grade dysplasia c) high grade dysplasia d) carcinoma'	Current availability of NHS statistics on an important public health issue is low.	Annual risk of oesophageal adenocarcinoma for Barrett's Oesophagus patients is 0.3% without dysplasia; 1% low grade dysplasia; 6% high grade dysplasia. A patient aged 30 with newly-developed Barrett's oesophagus may have a risk of 11-25% of developing OAC before the age of 80. See background document available from www.actionagainstheartburn.org.uk
4	4.1	Action Against Heartburn	Proposed Quality Standard	'Number of patients diagnosed with oesophageal high grade dysplasia referred for radio frequency ablation, endoscopic mucosal resection or surgical treatment'.	There is widespread inconsistency in relation to how patients diagnosed with high grade dysplasia are treated.	Radio frequency ablation offers an effective method of preventing further development of dysplasia and the risk of cancer developing, thereby avoiding expensive cancer surgery and other therapies.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
5	4.1	Cancer Research UK	GP access to secondary care expertise	The earlier a cancer is diagnosed, the better chance they have of successful treatment. Most cancer diagnoses start with attendance to a GP, and so anything to speed up diagnosis is important. This is identified in section 1.16.2	International comparisons of different healthcare systems have suggested that access to secondary care could be a factor which influences the speed of cancer diagnosis. GPs in England need better access to the advice of secondary care colleagues to assist with making difficult referral decisions.	http://www.sciencedirect.com/science/article/pii/S0277953614003980 Also in Achieving World-Class Cancer Outcomes: a Strategy for England 2015 – 2020, page 30
6	4.1	Cancer Research UK	Direct access to key investigative tests for suspected cancer – blood tests, chest x-ray, ultrasound, MRI, CT and endoscopy	Direct access to specific investigative tests has the potential to speed up diagnosis, in cases where the GP knows which test to order (rather than going via a secondary care specialist).	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). 22% of CCGs commissioned none of these. It was also a recommendation of the previous cancer strategy, 'Improving Outcomes' in 2011.	http://www.gponline.com/exclusive-half-gps-denied-access-cancer-scans/article/1322870 This is also recommended in Achieving World-Class Cancer Outcomes: a Strategy for England 2015 – 2020, as recommendation 17.
7	4.1	Cancer Research UK	Timeliness of investigation and	Increased pressure on diagnostic services may lead to long waits for undertaking tests or results being	Test and reporting will occur according to the 28 day ambition for patients to	https://www.gov.uk/government/news/from-2020-people-with-suspected-cancer-will-be-diagnosed-faster

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			reporting	reported – this may delay a cancer diagnosis.	receive a definitive diagnosis or the all-clear.	
8	4.1	Royal College of Paediatrics and Child Health	Time to diagnosis	Time to diagnosis seems to be greatest in those with bone tumours & sarcoma, and what evidence we have links negative outcome to TTD in these groups.	Exactly why is unclear still - low index of suspicion appears to be one area (in patients and HCP), inappropriate imagining a further element - when 'in the system' it's probably not particularly delayed. Brain tumour diagnosis has improved, but could be improved further by greater access to MRI brain scan & reporting. Acute leukaemia diagnosis sometimes takes a few weeks, but appears not to be linked to mortality/morbidity outcome. Renal tumours are tricky; they have a low TTD but appear to have higher-stage than in other European countries,	MAIN PROBLEM: No solid evidence exists regarding interventions to improve outcomes by shortening diagnostic for intervals in paediatric tumours The 2WW model for adult suspected cancer appears to be 'broken' in paeds - there are a wealth of reports in this area, many published in Arch Dis Child - particularly for lymphadenopathy referrals.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					implying later diagnosis. This could be probably addressed with open-access abdominal ultrasound & public/primary care education (cf the Headsmart model) but cost-effectiveness is extremely uncertain.	
9	4.1	The Brain Tumour Charity	Time to diagnosis for paediatric brain tumours.	There are a number of potential benefits that would arise from earlier diagnosis of brain tumours in children and young people. Brain tumours are the biggest cause of preventable or treatable illness in children (1-2). In the case of childhood sight impairment, evidence suggests that earlier diagnosis of brain tumours could lead to less morbidity after any treatment (1). In the longer term, a prolonged symptom interval is associated with the development of additional signs and symptoms such as increased cognitive deficits, endocrinopathies and visual loss (3).	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, was found to be 6.7 weeks in 2013. Whilst this represents an improvement from over 9 weeks in 2011, improvement is still needed to match the best international standards of 5 weeks. We were disappointed to see that due to the focus on positive predictive value (PPV) in the Guidelines on Suspected cancer:	The NICE Evidence-accredited Brain Pathways guideline (The brain pathways guideline: a guideline to assist healthcare professionals in the assessment of children who may have a brain tumour), in addition to the following publications, which were not identified by the literature search for the recently published suspected cancer guidance: • Wilne et al, Lancet Oncology, Volume 8, No. 8, p685–695, August 2007: http://www.rcpch.ac.uk/sites/default/files/Diagnosis%20of%20Brain%20Tumours%20in%20Children%20Guideline%20-%20Full%20report.pdf

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					recognition and referral, all of the detail on referral for symptoms of paediatric brain tumours present in the 2005 version of the guidelines was lost. We are concerned that this will have a detrimental effect on median diagnosis times, and this should be monitored to assess whether this is happening.	• Wilne et al Arch Dis Child doi:10.1136/adc.2009.162057 • Wilne et al BMJ 2013; 347 doi: http://dx.doi.org/10.1136/bmj.f5844 (Published 09 October 2013): http://learning.bmj.com/learning/module-intro/.html?moduleId=10046120 Other references: 1. Durnian JM, Cheesman R, Kumar A, Raja V, Newman W, Chandna A, Childhood sight impairment: a 10-year picture. Eye (2009); 24:112-117 2. Rahi JS, Cable N; British Childhood Visual Impairment Study Group, Severe visual impairment and blindness in children in the UK. Lancet (2003) 362:1359-65. 3. Wilne SC, Kennedy C, Jenkins A, Grout J, Mackie S, Koller, Grundy R, Walker D, Progression from first symptom to diagnosis in childhood brain tumours: a multicentre study (Abstract). Archives of Disease in

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
						Childhood. 2007; 92 (Supp 1). A69
10	4.2	Cancer Research UK	Safety-netting, or the active monitoring of people in primary care who have presented with symptoms	Active monitoring of symptoms in people at low risk (but not no risk) of having cancer to see if their risk of cancer changes (as stated in section 1.15); and also monitoring the outcome for patients who are sent for investigation, is an important factor to ensure diagnoses are not missed.	This was stated as a recommendation in Achieving World-Class Cancer Outcomes: a Strategy for England 2015 – 2020 (recommendation 18) and there may be variation in practice across the country.	
11	4.2	SCM 2	Safety netting procedures (1.14.9 – new for 2015 - plus 1.15.1 & 1.15.2, also news for 2015)	Dealing with suspected cancer is stressful. Patients need to know that the results of investigations will be reviewed and acted upon appropriately and in a timely way when cancer is suspected; and also to know that they can return and raise more questions later if their symptoms persist or change	Patients (and their carers) should be able to understand the diagnostic process and how any symptoms will be regarded, both when they present initially and if they need to return later. Reviewing the patient pathway ie tracking back from the point of [a later] diagnosis (when patients return for further investigations) might help to identify areas that need improvement earlier in the	The 2015 NHS Atlas of Variations in Healthcare maps the overall differences between CCGs in terms of cancers diagnosed at Stages 1 and 2 (Maps 12 ff refer; they apply to England and Wales) NCPES 2014 Benchmark Charts and Diagnostic Tests pp16-17 & ff https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					diagnostic process. It could be part of measuring the effectiveness of public awareness campaigns and GP practices.	national-cancer-patient-experience-survey-national-reports Routes to Diagnosis 2006-13 (pub. 2015) www.ncin.org.uk/publication/routes_to_diagnosis
12	4.2	Cancer Research UK	Timeliness of investigation and reporting	Increased pressure on diagnostic services may lead to long waits for undertaking tests or results being reported – this may delay a cancer diagnosis.	Test and reporting will occur according to the 28 day ambition for patients to receive a definitive diagnosis or the all-clear.	https://www.gov.uk/government/news/from-2020-people-with-suspected-cancer-will-be-diagnosed-faster
13	4.2	London Cancer	Referral of people with potential cancer: Communication of results of investigations initiated in primary care	Urgent results should be actioned promptly and appropriately to avoid misses. Otherwise results can sit in inboxes for unacceptable periods and delays may occur. This is how significant events arise.	With any 'new' processes there are always adverse events which can occur. The transition to 'urgent direct access' will require stringent protocols at each end of the diagnostic pathway to reduce adverse events. Eg. Acceptable routes to request these tests/ how result are communicated to primary care and acceptable timeframes for reporting.	Diagnostic and Imaging Dataset Annual Statistical Release, 2013/14 http://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2014/06/Annual-Statistical-Release-2013-14-DID-pdf-1118KB.pdf

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
14	4.3	Breast Cancer Now	Every woman under 30 with signs of suspected breast cancer is referred within two weeks.	When the NICE guideline on Suspected Cancer (NG12) was updated, the GDG took the decision to slightly restrict urgent referral options for people under 30. The effect of this is that someone under 30 presenting only with an unexplained breast lump will only get a non-urgent referral, whereas under the previous guideline they would have got an urgent referral if the lump had enlarged or was fixed and hard and/or if they had a family history of breast cancer. We note that at present this is likely to have a limited impact in England where the waiting time target for urgent and non-urgent referrals is currently the same at 2 weeks. However, we are concerned about the impact this could have in Wales where there is no official target for waiting times for urgent or non-urgent referrals. Recent Freedom of Information requests made by Breakthrough Breast Cancer in March 2015 revealed that waiting	It is essential to highlight that while breast cancer is uncommon in women under the age of 30, it does still occur. Research has shown that younger women with cancer symptoms are more likely to experience repeated GP appointments before being referred for specialist diagnosis and therefore attention must be paid to the possibility of breast cancer in younger women, especially in those with a family history of the disease.	See: Reference: Lyratzopoulos G, Neal RD, Barbiere JM, Rubin GP, Abel GA. (2012). Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England. The Lancet Oncology, 13(4), pp. 353-365.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				times for non-urgent referrals can be over 6 months in some areas. The fact that in the new NICE guideline on Suspected Cancer (NG12), it is no longer recommended that family history is taken into account when assessing the need for an urgent referral in people under 30, makes this situation all the more pertinent. This is because a family history of breast cancer may increase the patient's risk of developing it, and at a younger age. In particular, mutations in the BRCA1 or BRCA2 genes can lead to carriers developing breast cancer at a younger age than is usually expected.		
15	4.3	British Thoracic Society	People reporting one or more symptoms suggesting lung cancer are referred within 1 week of presentation for a chest X-ray or directly to a chest physician who is a core member of the lung cancer	We note that there is overlap with the current NICE lung cancer quality standard which states "People reporting one or more symptoms suggesting lung cancer are referred within 1 week of presentation for a chest X-ray or directly to a chest physician who is a core member of the lung cancer multidisciplinary team."	We support the emphasis on referral for CXR as the first step and if this is normal only refer on for clinic in very specific circumstances i.e. are aged 40 and over with unexplained haemoptysis. While we note that there will not be specific	

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			multidisciplinary team."		standards for each tumour site - a generic standard could be the proportion of 2 week wait referrals that meet the NICE referral criteria should be >95%. Alternatively, the proportion of patients diagnosed with cancer who met the referral criteria but were not referred should be <5%. The number of GP consultations prior to the CXR/clinic referral could also be included although this may be more difficult to measure. We also note that it is important to ensure that GPs/patients are aware of the importance of recognising the first episode of haemoptsis that may precede the diagnosis by several months.	
16	4.3	Cancer Research UK	Timeliness of investigation and reporting	Increased pressure on diagnostic services may lead to long waits for undertaking tests or results being	Test and reporting will occur according to the 28 day ambition for patients to	https://www.gov.uk/government/news/from-2020-people-with-suspected-cancer-will-be-diagnosed-faster

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				reported – this may delay a cancer diagnosis.	receive a definitive diagnosis or the all-clear.	
17	4.3	East Lancashire Healthcare	Key area for quality improvement 3	Patients presenting with symptoms suggesting lung cancer have a chest x-ray via their general practitioner to be reported within 1 week	It is established that the positive predictive value for 2-week rule referrals for suspected lung cancer can reach 20%-30% when a chest x-ray is ordered by the primary care practitioner prior to referral. Furthermore, the patient arrives in secondary care with an important investigation 'already done'.	I suspect this may be done in many cases – the object is to formally ensure that all GPs do this and to specify a time for receiving the result
18	4.3	London Cancer	Referral of people with potential cancer: Communication of results of investigations initiated in primary care.	Urgent results should be actioned promptly and appropriately to avoid misses. Otherwise results can sit in inboxes for unacceptable periods and delays may occur. This is how significant events arise.	"With any 'new' processes there are always adverse events which can occur. The transition to 'urgent direct access' will require stringent protocols at each end of the diagnostic pathway to reduce adverse events.	"Diagnostic and Imaging Dataset Annual Statistical Release, 2013/14 http://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2014/06/Annual-Statistical-Release-2013-14-DID-pdf-1118KB.pdf"
19	4.3	SCM 1	Urgent direct access upper GI endoscopy for suspected gastro-oesophageal cancers	NICE guidance recommends direct access upper GI endoscopy for people with suspected gastric and oesophageal cancers. The thresholds for referral are stipulated in the guidance: people • with dysphagia or	Prior to the guidance these people would be referred for an urgent cancer appointment with a specialist and would subsequently receive an upper GI endoscopy	

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				• aged 55 and over with weight loss and any of the following: • upper abdominal pain • reflux • dyspepsia.	initiated in secondary care. Approximately 80% of these people would not have cancer. By starting with the urgent direct access endoscopy, time to diagnosis can potentially be shortened for those who do have cancer and an unnecessary urgent cancer appointment can be avoided for those who do not have cancer; therefore freeing up resources.	
20	4.3	The Brain Tumour Charity	Urgent referral for MRI scan where Brain/CNS cancer is suspected within two weeks in children and young people (or an appointment within 48 hours)	Urgent referral for MRI will be an important component of bringing diagnosis times for paediatric brain tumours in line with the best internationally, and furthermore will help meet the Cancer Taskforce's target of diagnosis within four weeks of referral.	By making urgent referral for MRI scan in children and young people a key area for quality improvement, there is a greater chance of diagnosing brain tumours at an earlier stage, and an opportunity to reduce the long-term disability that children with a brain tumour face following treatment.	The brain pathways guideline: a guideline to assist healthcare professionals in the assessment of children who may have a brain tumour has received NICE NHS accreditation and was endorsed by the Royal College of Paediatrics and Child Health (RCPCH). Since the campaign was launched in 2011, there has been a reduction in the diagnosis times of children from 9.3 weeks to 6.7 weeks.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
						The research which underpins the HeadSmart campaign looks at symptom onset and routes to diagnosis: • Wilne SC, Koller K, Collier J, Kennedy C, Grundy R, Walker D, The diagnosis of brain tumours in children: a guideline to assist healthcare professionals in the assessment of children who may have a brain tumour, Arch Dis Child. 2010 Jul;95(7):534-9. Epub 2010 Apr 6: http://www.rcpch.ac.uk/sites/default/files/Diagnosis%20of%20Brain%20Tumours%20in%20Children%20Guideline%20-%20Full%20report.pdf In reference to reducing the symptom interval of children diagnosed with a brain tumour, there are two research papers which look at presentations of childhood CNS tumours and progression from first symptom to diagnosis: 1. Wilne SC, Collier J,

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
						Kennedy C, Koller K, Grundy R, Walker D. Presentation of childhood CNS cancers: a multicentre study. Archives of Disease in Childhood. 2007; 92 (Supp 1): A69 2. Wilne SC, Collier J, Kennedy C, Koller K, Grundy R, Walker D. Presentation of childhood CNS tumours: a systematic review of meta-analysis. Lancet Oncology 2007 Aug; 8 (8): 685-695
21	4.3	Breast Cancer Now	When considering a referral for suspected cancer, family and personal history is taken into account.	Of all women who develop breast cancer, about one in five has a moderate or significant family history of the disease. If there is a history of breast cancer or some other cancers (especially ovarian cancer) this may increase the patient's risk of developing breast cancer, and at a younger age. In particular, women who have a mutation in the BRCA1 or BRCA2 genes have a substantially increased risk of developing breast cancer, by the age of 70, to between 65 and 85 percent for BRCA1 mutations and between 40 and 85 percent for BRCA2. This	When the NICE guideline on Suspected Cancer (NG12) was updated, the GDG took the decision to remove references to the relevance of family and personal history. We appreciate the rationale adopted by the GDG with regards to the separation of risk associated with the symptom profile, and risk associated with family or personal history of breast cancer.	See: Soerjomataram I, Louwman WJ, Lemmens VEPP, et al. (2005). Risks of second primary breast and urogenital cancer following female breast cancer in the south of The Netherlands, 1972–2001. European Journal of Cancer, 41(15), pp. 2331-37. Rubino C, Arriagada R, Delaloge S, et al. (2009). Relation of risk of contralateral breast cancer to the interval since the first primary tumour. British Journal of Cancer, 102(1), pp. 213-19.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				compares with the 12.5 percent lifetime risk for the average woman in the UK. These mutations can also lead to carriers developing breast cancer at a younger age than is usually expected. Similarly, cohort studies show that breast cancer survivors have between two and five times increased risk of developing a second primary breast cancer. Excluding 'second cancers' found within two years of the primary, which may actually be spread from the primary tumour, the risk of second primary breast cancer remains significantly elevated for 20 years from the primary diagnosis. Primary care practitioners should therefore be aware of the relevance of a family and personal history of cancer when assessing potential symptoms of breast cancer. People in these two groups warrant special attention because of their family or personal circumstances, and these	However, given that the risk conferred by a family or personal history of breast cancer can be significant (up to an 85% lifetime risk for people with a mutation in the BRCA1 or BRCA2 genes), we feel that it is imperative for GPs to be mindful of this when assessing the need for referral. Otherwise, we feel that the removal of the reference to family and personal history could have negative unintended consequences.	Dong C, Hemminki K. (2001). Second primary neoplasms in 633,964 cancer patients in Sweden, 1958–1996. International Journal of Cancer, 93(2), pp.155-61.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				circumstances should be drawn to the attention of GPs.		
22	4.4	British Association of Dermatologists	Online cancer referral portal	All cancers should be referred by GP practices using an online platform such as the e-referral management system. The system should have mandatory fields which are completed by the GP to help determine the appropriate referral pathway to an 18-week wait or 2-week wait service. This should provide an option for diagnostic images where appropriate, along with sufficient patient medical history to accompany the referral. The referral system should be able to facilitate triage, advice and guidance for 18-week wait referrals. The system must be able to provide reports on referral data to CCG commissioners and allow the GP to track the patient’s referral progress. The system should also allow directly bookable appointments to be made by the patient online.	The characteristics of patients and their clinical presentations referred for possible cancers is rarely examined to determine the sensitivity and specificity of the referring process or the abilities of individual referring clinicians. This is down to the lack of data in the system, as the current referral mechanism is through Word templates which do not compile a database of relevant referral information for those with and without a final diagnosis of cancer. In turn, this makes it very difficult to provide good casemix/clinical data for relevant outcomes, including “no cancer” diagnosis outside of the required MDT diagnostic recorded data. An online platform aligned with Public Health England ENCORE COSD systems would help	The evidence for this is based on the models used by supermarkets online which rapidly capture data on the manner of our referring, modify their menu items offered to use and keep stock data on their warehouse as an analogy to the diagnostic hit rate of the cancer referral system. The need for the process is based on the absence of such intelligent real-time processes in the enormously complex system of cancer referral and the challenges for cancer registration of some cancer types.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					commence a line of continuity to the cancer registration process from the commencement of the process.	
23	4.4	University Hospitals Bristol NHS Foundation Trust	Online cancer referral portal	All cancers should be referred through an online platform that has scope to make fields mandatory, captures cumulative data, enables feedback per practice and is attributed to a clinician login. It needs to have a front end that has a patient section and a login section that allows clinicians to refer or undertake telemedicine interactions relating to cancer diagnosis and care. The back end of the system could be Choose and Book/e-Referral.	The characteristics of patients and their clinical presentations referred for possible cancers is rarely examined to determine the sensitivity and specificity of the referring process or the abilities of individual referring clinicians. This is down to the lack of data in the system as the current referral mechanism is through Word templates which do not compile a database of relevant referral information for those with and without a final diagnosis of cancer. In turn this makes it very difficult to provide good casemix/clinical data for relevant outcomes, including “no cancer” diagnosis. An online platform aligned with Public Health England ENCORE	The evidence for this is based on the models used by supermarkets online which rapidly captures data on the manner of our referring, modifies their menu items offered to use and keeps stock data on their warehouse as an analogy to the diagnostic hit rate of the cancer referral system. The need for the process is based on the absence of such intelligent real time processes in the enormously complex system of cancer referral and the challenges for cancer registration of some cancer types.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					COSD systems would help commence a line of continuity to the cancer registration process from the commencement of the process.	
24	4.4	Cancer Research UK	Investigation and referral outside of NICE criteria	People who prompt clinical suspicion of cancer should be offered further investigation according to a GP's clinical judgement – as there is the potential for some symptoms to fall outside of the NICE guidelines but still warrant investigation.	This was stated as a recommendation in Achieving World-Class Cancer Outcomes: a Strategy for England 2015 – 2020 (recommendation 16) as it has been suggested that people would opt for further investigation at a lower than 3% PPV.	http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70588-6/abstract
25	4.4	Children's Cancer and Leukaemia Group	Key area for quality improvement 1	Wilne et al Lancet OncologyVolume 8, No. 8, p685–695, August 2007 http://www.rcpch.ac.uk/sites/default/files/Diagnosis%20of%20Brain%20Tumours%20in%20Children%20Guideline%20-%20Full%20report.pdf Wilne et al Arch Dis Child doi:10.1136/adc.2009.162057 Wilne et al BMJ 2013; 347 doi:		

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				http://dx.doi.org/10.1136/bmj.f5844 (Published 09 October 2013) http://learning.bmj.com/learning/module-intro/.html?moduleId=10046120 The Chldren's Cancer and Leukaemia Group participate in the pubic and professional awareness campaign and provided the Quality Improvement data which has demonstrated that total diagnostic interval, as measured in regional and national cohort studies using comparable techniques, has reduced from 14.4 weeks median to 6.7 weeks median between 2006 and 2014. Prior to the publication of the RCPCH Guidance and the HeadSmart Awareness campaign there had been several studies where no change in symptom interval was identified. (Neuro-Oncology 2015 in press) We would commend HeadSmart Be Brain Tumour Aware to the NICE Cancer Referral Guidance Group as an example of a QI		

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				method project, which has produced a demonstrable impact on referral practice across the UK and which is compliant with methods and standards accredited by NICE in their role of managing NHS Evidence. We would raw NICE attention to the public's perception summarised in this newshot that the reason UK brain tumour survival figures are well behind Europe is because our referral practice is well behind Europe. http://www.channel4.com/news/britain-brain-tumour-cancer-treatment-survival-europe-rate We would be interested in the NICE response to this information which seems to have been omitted from its panel's consideration during the drafting of the recently published guidance document and means that there are two sets of guidance accredited by NICE methodologies for diagnosis of brain tumour in children, one which is not evidence based		

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				because the methodology selected is not applicable to rare cancers in childhood and the other which is QI based using awareness methodology which is accredited by NHS Evidence and can be demonstrated to have delivered a change in practice and be acceptable to the public and profession .		
26	4.4	Royal College of General Practitioners	People with newly identified DVT	Are people with newly identified DVT being assessed for possible cancer as a cause routinely and in appropriate timeframes		
27	4.4	Royal College of General Practitioners	People with appetite or weight loss	Are people with appetite or weight loss being assessed promptly in primary care and Ix /referred in appropriate timeframes.		
28	4.4	Royal College of Physicians	General	"Our experts would like to highlight that unlike other cancers, it is preferable not to diagnose many prostate cancers. Harmless, indolent prostate cancers are better left undiagnosed. Furthermore, the rate of progression of prostate cancer is typically very slow, reducing the urgency around diagnostic waits.		

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Our experts feel that the results of the Stockholm 3 study, due to be published this month, are likely to revolutionise prostate cancer diagnostics. The study will show that a multiplex biomarker panel reduces the need for prostate biopsy, reduces the detection of indolent cancers but increases the detection of high grade cancers. "		
29	4.4	Breast Cancer Now	GPs use all available opportunities to inform and educate patients about signs and symptoms of relevant cancers.	It is essential for people to be fully informed about possible symptoms of cancer because early detection saves lives. In breast cancer, there is a need for greater awareness about non-lump signs and symptoms because, while there is generally high awareness of a breast lump as a possible breast cancer indicator, awareness of non-lump symptoms is lower, and can lead to delays in presentation.	When the NICE guideline on Suspected Cancer (NG12) was updated, one of the impacts of this was that under the new guideline, someone under 50 presenting only with nipple discharge, retraction or other nipple changes of concern, will no longer get a referral for suspected cancer, whereas under the previous guideline they would have got an urgent referral for unilateral bloody nipple discharge, nipple distortion of recent onset, or unilateral nipple change that did not respond to	In September 2014 Breakthrough Breast Cancer (one of the two charities which merged to form Breast Cancer Now) commissioned a nationally representative online survey of 1,082 women across GB to ask them about breast cancer symptoms and screening. They found that 85% of women were spontaneously aware that lump(s) in the breast are a symptom compared with 24% – change in the size or shape of the breast, 34% – changes to the skin, 21% – changes to the appearance of the nipple. Similarly, when choosing from a

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					topical treatment. Given that (in breast cancer) nipple changes are the only symptom given a higher age limit than 30 in the new guideline, we are concerned about the impact on people under the age of 50 who present with nipple changes. In particular, we feel it is imperative that these people understand that this can still be a symptom of breast cancer, and are informed that if the symptoms recur later in life they should re-contact their GP. We are concerned that younger women could be reassured that nipple changes are not something to worry about, and may ignore them later in life. This is all the more important because when the NICE guideline on Suspected Cancer (NG12) was updated, the recommendation to	list of potential symptoms women's knowledge of non-lump signs was also lower: 93% were aware that lump(s) in the breast are a sign, compared with 77% – change in the size or shape of the breast, 69% – changes to the skin, 82% – changes to the appearance of the nipple. There is also clear evidence that clinicians are likely to approach non-lump symptoms differently. The National Audit of Cancer Diagnosis in Primary Care in 2009/10 looked at the primary care pathway to cancer diagnosis; those whose primary presenting symptom was a lump in the breast were more likely to be referred through the two week urgent referral pathway than those presenting with non-lump symptoms e.g. 84 percent of those presenting primarily with a lump compared with 73 percent with a change in breast appearance and 67 percent with nipple discharge. See also:

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					encourage all patients to be breast aware was removed.	Macleod U, Mitchell ED, Burgess C, Macdonald S and Ramirez AJ. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers, British Journal of Cancer, 101, S92-S101.
30	4.4	Breast Cancer Now	Women over 70 are routinely reminded that they are still at risk of breast cancer and are able to self-refer to breast screening.	The risk of breast cancer increases with age – a third of breast cancer cases and more than half of breast cancer deaths in the UK occur in women over the age of 70. Knowing the different signs and symptoms of breast cancer is a vital component of being breast aware. In addition, breast screening plays an important role in the early identification and diagnosis of breast cancer. Women between 50 and 70 years of age are routinely invited every three years for breast screening by the NHS Breast Screening Programme, but whilst breast screening is still available to women over 70, they are required to make their own appointments.	Many older women are unlikely to be aware of many non-lump signs and symptoms. Evidence also suggests that older women are less likely to be breast aware, with one in five women aged over 70 years reported to never touch, feel or look at their breasts. Poor knowledge of age-related risk for breast cancer is also of particular concern in older women, and this has been attributed in part to women incorrectly assuming they are no longer at risk of developing the disease after routine NHS breast screening invitations cease.	The All Party Parliamentary Group on Breast Cancer conducted an inquiry into older people and breast cancer in 2013 and the report from this inquiry contains further information about breast awareness and screening in older people. This report can be found at: http://breastcancernow.org/sites/default/files/public/age-is-just-a-number-report.pdf.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					Interventions at a woman's final routine screening appointment and at GP appointments is essential to ensure that older women know that their risk of breast cancer increases with ages. In addition, these women need to be confident and competent to regularly check their breasts and be made aware that opportunities for breast screening do not cease along with routine breast screening invitations.	
31	4.4	Cancer Research UK	Clear communication with patient	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 should be clearly communicated to the patient, as stated in 1.14.3	Achieving World-Class Cancer Outcomes: a Strategy for England 2015 – 2020 identified a strategic priority should be for patient experience to be on a par with clinical outcomes, and communication is a key part of this.	
32	4.4	East Lancashire Healthcare	Key area for quality improvement 2	All patients that are identified to be at high risk of cancer (for example, very heavy smokers in relation to lung and head and neck cancers) receive, via their general	It is important for several reasons. Firstly, the vast majority of cancers such as lung and head and neck are lifestyle (smoking)	A very significant proportion of delay in diagnosis in certain cancers is patient delay, as opposed to primary care or secondary care delay. This is

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				practitioner, targeted information on the symptoms and signs of the cancers they are at risk of developing.	related. Secondly, many of these cancers present at the advanced stage (if not actually incurable) – information on symptoms could encourage earlier presentation. Thirdly, it represents targeted information at the ‘right’ patients. Fourthly, such a measure could help with the elimination of health inequalities.	particularly so with cancers associated with low socio-economic status (such as lung).
33	4.4	Prostate Cancer UK	Information and choice for patients	Improved information and choice for patients before referral for suspected cancer can lead to improved outcomes. In relation to early detection of prostate cancer, patients can play a key part in identifying their own risk and having a PSA test. Men over 50 are currently entitled to have a PSA test free on the NHS, provided they have discussed the pros and cons with their GP. However, our research shows that 14% of GPs are not aware of this (14). Improvement is therefore needed so that primary healthcare professionals are able to provide balanced information to all men	Improved information and support in primary care is particularly important for men with suspected prostate cancer due to the complexity of deciding whether to have a PSA test. The decision to have a PSA test is very difficult for men as the usefulness of the PSA test (the only widely available test for prostate cancer) is limited due to poor sensitivity and specificity (19). Men therefore require substantial information and support from primary care	Reference List 1. The Independent Cancer Taskforce. Achiveing World-Class Cancer Outcomes - A Strategy for England [Internet]. [cited 2015 Sep 18]. Available from: http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf 2. prostate-booklet-text.pdf [Internet]. [cited 2013 Jun 25]. Available from: http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				over 50 years and younger men at higher risk of prostate cancer on the pros and cons of the PSA test to help them come to an informed decision on whether or not to have this. Providing patients with information about the care they can expect also plays an essential role in ensuring a positive experience of care and referral. Good information helps patients understand the reason for their referral and what to expect, and can reduce anxiety, promote psychological wellbeing and increase their sense of control (17). Information is also important in providing knowledge to enable meaningful participation in decision-making (18). People being referred for suspected cancer should therefore be supported by a health care professional to fully understand the reasons for referral, and have the opportunity to ask follow up questions so they are fully supported to understand the implications of future tests for	professionals to enable them to make an informed decision. However, studies have shown men often experience deficiencies in pre-test information and discussion (20). This is consistent with our own research. In an online survey PCUK carried out in 2014 with 569 men with prostate cancer (21), responses to views on experience of referral showed 44% of men with prostate cancer we surveyed said their GP had not talked them through the pros and cons of the PSA test before they had the test. A separate survey carried out with 500 GPs on behalf of PCUK also showed 90% of GPs agree the provision of patient information and support would help them support men concerned about prostate health (14). It is important to note that	text.pdf 3. Cancer Research UK. Prostate cancer incidence statistics: By Age (2009-2011) [Internet]. 2014 [cited 2014 May 19]. Available from: http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/incidence#heading-One 4. Lloyd T, Hounsome L, Mehay A, Mee S, Verne J, Cooper A. Lifetime risk of being diagnosed with, or dying from, prostate cancer by major ethnic group in England 2008–2010. BMC Med. 2015 Jul 30;13(1):171. 5. Johns L, Houlston R. A systematic review and meta-analysis of familial prostate cancer risk. BJU Int. 2003;91(9):789–94. 6. McPherson K, Steel CM, Dixon JM. Breast cancer - epidemiology, risk factors, and genetics. ABC Breast Dis. 2000;572:24. 7. Castro E, Eeles R. The role of BRCA1 and BRCA2 in prostate cancer. Asian J Androl.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				them. Information on the risks, benefits, limitations and availability of diagnostics such as biopsy and mpMRI is also important for men in making informed decisions about whether or not to have these tests when referred for suspected prostate cancer. It important to make information available in a variety of formats to best help patients understand what is happening and help them prepare for the referral appointment. Men with prostate cancer particularly value information that is provided verbally, either by phone or face to face. It is also important to provide easy to understand written information at the point of referral, as this can give patients something to consider in their own time. Friends and relatives also play an important part in helping men being treated for prostate cancer so it is important that their information needs are also adequately addressed.	men with urinary tract symptoms would also benefit from having balanced information about the PSA test before it is taken. Bothersome lower urinary tract symptoms are common and can occur in up to 30% of men older than 65 years (15), many of whom will not have prostate cancer. Having the pros, cons and limitations of the PSA test fully explained is important in supporting these men to make an informed decision, and could also help avoid unnecessary anxiety about the test, particularly if the man is found to have a high PSA score. Our evidence on men's experience of referral shows there is also significant scope for general improvement in the range and quality of information available to men in primary care before	2012;14(3):409–14. 8. Thompson D, Easton DF. Cancer incidence in BRCA1 mutation carriers. J Natl Cancer Inst. 2002;94(18):1358–65. 9. Mitra AV, Bancroft EK, Barbachano Y, Page EC, Foster CS, Jameson C, et al. Targeted prostate cancer screening in men with mutations in BRCA1 and BRCA2 detects aggressive prostate cancer: preliminary analysis of the results of the IMPACT study: TARGETED PROSTATE CANCER SCREENING. BJU Int. 2011 Jan;107(1):28–39. 10. Burford D, Kirby M, Austoker J. Prostate Cancer Risk Management Programme information for primary care; PSA testing in asymptomatic men. Evidence document. NHS Cancer Screening Programmes [Internet]. 2010. Available from: http://www.cancerscreening.nhs.uk/prostate/pcrmp-guide-2.html 11. Schröder FH, Hugosson J, Roobol MJ, Tammela TLJ, Ciatto S, Nelen V, et al. Screening and prostate-cancer mortality in a

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					referral for suspected cancer. Information is very important for men with suspected prostate cancer, but they often do not receive the information they need. Our survey showed: • 90.8% of respondents said it was very important for men with suspected prostate cancer to receive information about how long it would take to get a diagnosis. The survey showed that 60.4% did not receive this information from their GP when they were referred. • 84.6% said information on the types of tests available for prostate cancer after referral is very important. The survey showed that 41.5% did not receive this information from their GP. • 86.7% of respondents said information on risks associated with tests that might be carried out is very important for men with	randomized European study. N Engl J Med. 2009 Mar 26;360(13):1320–8. 12. Thompson IM, Pauler DK, Goodman PJ, Tangen CM, Lucia MS, Parnes HL, et al. Prevalence of prostate cancer among men with a prostate-specific antigen level < or =4.0 ng per milliliter. N Engl J Med. 2004 May 27;350(22):2239–46. 13. Abdel-Rahman, M, Stockton, D, Rachet, B, Hakulinen, T, Coleman, M. P. What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? Br J Cancer. 2009;101:115–24. 14. Kantar Health. Figures from a survey of 500 GPs in the UK conducted by Kantar Health on behalf of Prostate Cancer UK in January 2014. 2014. 15. NICE Clinical Guidance 97. Lower urinary tract symptoms in men: assessment and management [Internet] 2015. Available from: guidance-lower-urinary-tract-symptoms-in-men-assessment-and-management-pdf [Internet]. [cited 2015 Sep

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					suspected prostate cancer. This survey showed that 63.5% of respondents did not receive any information on these risks from their GP. • 92.1% said knowing how long they should wait for an appointment was very important. The survey showed that 47.4% were not told by their GP when their referral appointment would be. • 87.8% said information on prostate cancer was very important. The survey showed that 48.1% did not receive this information from their GP. Further to this, the National Cancer Patient Experience Survey (NCPES) shows 20% cancer patients say they did not receive any written information about the type of cancer that they had during the whole treatment pathway (22). • 79.5% said it was very important to be given	23]. Available from: https://www.nice.org.uk/guidance/cg97/resources/guidance-lower-urinary-tract-symptoms-in-men-assessment-and-management-pdf 16. Risky leap puts us on the path to a big change in diagnosis | Prostate Cancer UK [Internet]. [cited 2015 Sep 23]. Available from: http://prostatecanceruk.org/about-us/news-and-views/2015/1/risk-assessment-update-blog 17. Ream E, Richardson A. The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. Eur J Cancer Care (Engl). 1996 Sep;5(3):132–8. 18. Department of Health. Improving Outcomes: A Strategy for Cancer [Internet]. 2011. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf 19. Evans R, Joseph-Williams N, Edwards A, Newcombe RG, Wright P, Kinnersley P, et al.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					information about what to expect. The survey showed that 46.2% were not given this information by their GP (21). When asked how they would like to receive information from their GP or nurse regarding prostate cancer, 59.4% said they would prefer a verbal discussion either in person or by the phone. Nearly a third (31.3%) said they wanted a combination of 2 or more of the following: a discussion in person or over the phone, information to read, links to relevant websites and online forums (21).	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. 20. Sinfield P, Baker R, Camosso-Stefinovic J, Colman AM, Tarrant C, Mellon JK, et al. Men’s and carers’ experiences of care for prostate cancer: a narrative literature review. Health Expect Int J Public Particip Health Care Health Policy. 2009 Sep;12(3):301–12. 21. 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. 22. Quality Health for NHS England. Cancer Patient Experience Survey 2014 National Report [Internet]. 2014. Available from: http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
						survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports/688-2013-national-cancer-patient-experience-survey-national-report-pdf/file
34	4.4	SCM 2 (DR)	1. Patient information and support (see 1.14.5 and 1.14.9, both new for 2015)	This would then accord with the NICE Patient Experience quality statem about shared decision making and informed choice which sadly seems still to be lacking for many cancer patients and their carers.	Despite previous work and guidance in this area the Independent Cancer Taskforce reported that "perhaps the most disappointing aspect of [their] work has been the countless stories …...from patients and their carers of poor communication and sub-optimal co-ordination of care" The ICT report identified the need for "meaningful metrics" to encourage providers to focus on patient experience, expecting those metrics to be embedded in the NHS	NICE Patient Experience Quality Statements: especially 6,12 and14, http://www.nice.org.uk/guidance/qs15/chapter/List-of-quality-statements Please see the Independent Cancer Taskforce Report of July 2015 for full details of the six strategic priorities to boost cancer survival and transform patient experience https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf The report also includes the proposal "to establish patient experience as being on a par with clinical effectiveness and

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					accountability framework Currently there is “a disconnect between incentive systems and patient experience outcomes” and “best practice tariffs do not reflect cancer best practice outside research settings” (See ICT 6.2)	safety” (Executive Summary refers)
35	4.4	Teenage Cancer Trust	People with suspected cancer should be given information on their referral covering all areas highlighted in section 1.14.15 of the guideline.	There is good evidence that patients who have a poor understanding of their condition and treatment report worse patient experience. This is particularly prevalent among young people with cancer, highlighting the need for information to be provided in an age-appropriate manner.	Patients, including young people with cancer, often report poor experiences with GPs and low understanding of their condition and treatment . There are also gaps in information provision, particularly between diagnosis and the start of treatment.	As cited, the National Cancer Patient Experience Survey demonstrates the impact of information provision on patient experience.
36	4.5	London Cancer	"Referral of people with potential cancer: Communication with patients that they have been referred on an urgent pathway to exclude a diagnosis of cancer.	Patients are not always aware of the clinical concern about the urgency of their need for rapid investigation. This can hamper arrangements to slot them into an urgent appointment system or lead to patients changing their appointments electronically without being aware of the	Proper engagement with patients will ensure timely arrival at a definitive diagnosis for both the patient and their GP. If cancer is diagnosed, speeding up the front end of the pathway will improve time to treatment and	http://londoncancer.org/media/48492/2wk-referral-patient-leaflet.pdf http://londoncancer.org/media/124336/patient-information-for-urgent-referrals.pdf

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				potential adverse consequences of delay	hence outcomes in many cases.	
37	4.5	British Association of Dermatologists	Increasing diagnostic ability of GPS in referral of suspected skin cancer	There are considerable numbers of benign lesions and BCCs which should be clinically obvious being referred on a 2-week wait pathway rather than an 18-week wait pathway. This is producing significant strain on secondary care services and leading to patients referred with more significant skin problems not being seen and treated within the 2-week and 18-week governmental targets.	With increasing incidence of high risk BCC, melanoma and SCC, it is crucial that increased diagnostic accuracy at GP level is increased to ensure the correct referral pathway is made. Undergraduate and postgraduate training in Dermatology is inadequate given the proportion of a GP's work which is related to skin. Clinical indicators or checklists are important for GPs to use when diagnosing a skin lesion.	Numerous published audits. NCIN data on projected increased incidences of skin cancer until at least 2024. HES referral data for dermatology shows increases in general to dermatology departments.
38	4.5	Cancer Research UK	Application and communication of the guidelines	The guidelines need to be well-communicated so that when people present to primary care, they will be seen by a GP who is aware of and draws on the NICE guidelines in their practice.	When surveyed, nearly one in five GPs were not aware that the guidelines were updated in June, and only a third of GPs understand how the updated guidelines will alter their management of patients.	MedeConnect Healthcare Insight, Omnibus 'NICE Cancer Referral Guidelines' Survey, July 2015. 2015, Cancer Research UK. Also in Achieving World-Class Cancer Outcomes: a Strategy for England 2015 – 2020, recommendation 16.
39	4.5	East Lancashire	GP training (Key area for quality	All general medical practitioners undertake a formal 1-day course in	The object is to (1) provide support and enhancement	There is good evidence that 2-week rule referral rates of

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Healthcare	improvement 1)	the early recognition of cancer every 3 years.	to the existing NICE guidelines on 2-week referral of cancer and (2) provide training to improve the accuracy (i.e. positive predictive value or 'conversion rate') of GP referrals	suspected cancer can vary between GPs, working with similar populations, by as much as three times.
40	4.5	London Cancer	Recognition of cancer: GP education adapted to new guidance	It is widely known that early cancer detections lead to better prognosis and patient QOL/feedback. Moving the shift from RED flags to pre-red flags. Education of the primary care clinicians who need to have the understanding of these of non-specific symptoms or patterns of disease presentation that could be cancer is pivotal to the process of earlier diagnosis.	Education is delivered to GPs through various means – locally through the CCG if they hold a cancer event, charities: Macmillan/CRUK, online education eg. RCGP modules. There is no systematic or obligatory/incentivised route for ensuring the doctor is up to date. Particular if they are not part of a routine medical system eg. Locum, on extended leave etc. GP practice profiles demonstrate considerable variation in use of the urgent (2WW) referral pathway across England	GP practice profiles, showing variation in use of 2WW referral route Ongoing projects on GP referral styles (Macmillan) and Q Cancer pilots being run in London to assess impact of GP use of decision support tools
41	4.5	University	Increasing	There are considerable numbers	With increasing incidence	Numerous published audits.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Hospitals Bristol NHS Foundation Trust	diagnositic ability of GPS inreferral of suspected skin cancer	of benign lesions which should be clinically obvious being referred on a 2WW pathway. This is producing significant strain on secondary care services and leading to patients with significant problems breaching governmental targets	of Melanoma and Squamous Cell Carcinoma it is crucial that increased diagnostic accuracy at GP level is increased. Undergraduate and Postgraduate training in Dermatology is inadequate given the proportion of a GP's work which is related to skin.	NCIN data on projected increased incidences of skin cancer until at least 2024.
42	4.5	Royal College of General Practitioners	QI recommendation about practices looking into cases where time from presentation to that of referral/suspected cancer investigations was over a certain length of time	Perhaps also worth having some sort of QI recommendation about practices looking into cases where time from presentation to that of referral/suspected cancer investigations was over a certain length of time. This would need to be done in a very no blame QI way in order to make it valuable: not sure how easy it would be to write a simple statement re this.		
43	4.5	Royal College of General Practitioners	Emergency presentations	Look at emergency presentations to see whether these were missed in primary care and if so why.		
44	4.5	Royal College of General Practitioners	Quality improvement/quality maintenance	With the increased workload this guideline is likely to put on secondary care would be good to look at quality improvement/quality maintenance in terms of meeting		

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				the target for suspected cancer referrals being seen within 2 weeks in secondary care. This applies to all cancer types. 2) although, this quality standard cannot cover all specific types of cancer within its scope, are there any significant areas for quality improvement around the recognition and referral of suspected cancer that relate to specific types of cancer that cannot be covered by general quality statements?		
45	General	Association of Breast Surgery	No comments	This is just to say that there are no comments from the Association of Breast Surgery as we are happy with the proposed pathway of care and the urgent cancer referral.		-
46	General	NHS England	Key area for quality improvement 1	This is a very broad QS proposal and unlikely to improve much on the existing individual Cancer documents.	As far as lung cancer is concerned the steps will need to be around public awareness, early and accurate GP diagnosis of all respiratory conditions in the relevant demographic and rapid access to diagnostics and specialist investigation. I can't think that this is different elsewhere except where	I am not aware of any work that identifies why exactly 30% of lung cancer patients present as emergencies but I expect cancer colleagues may know. It will be a combination of patient factors and diagnostic delay.

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					screening programmes are in place.	
47	General	Royal College of General Practitioners	Things that have changed in this guideline	1) - Use of FOB sampling outside of screening in the suggested situations 2) - Appropriate use of melanoma 7 point check list 3) - CT scan for new onset DM with weight loss >60 years 4) - Direct access MRI for brain tumours: Or CT if contraindicated.		
48	General	Royal College of Physicians	General	The RCP is grateful for the opportunity to respond to the NICE quality standard topic engagement exercise on referral for suspected cancer. We have liaised with a wide number of experts from various specialties and we have had some feedback within the consultation timeframe. We would like to formally endorse the response from the British Thoracic Society, and submit the following comments from our experts in prostate cancer.		
49	General	SCM 2 (DR)	Research relating to patient experience of	More qualitative information from patients and their carers might	The Topic Guidelines recognise that information	NICE Topic Overview, 2.4

ID	Related section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			the above in the diagnostic process	encourage commissioners to take these aspects into account in their arrangements (as per 2005)	on patient experience and also about patient information needs is lacking	NCPES 2014 (v.s) Routes to Diagnosis (v.s.)
50	General	The Royal College of Nursing	No comments	The Royal College of Nursing have no comments to submit to inform on the above topic engagement at this time. Thank you for the opportunity. We look forward to participating in the next stage of development.		