NATIONAL INSTITUTE FOR HEALTH AND   
CARE EXCELLENCE

Quality standards

Briefing paper: Suspected cancer (update)

**Quality Standards Advisory Committee meeting**: 13 June 2023

[1 Introduction 2](#_Toc141283841)

[3 Summary of suggestions 9](#_Toc141283850)

[4 Suggested improvement areas 12](#_Toc141283852)

[4.1 Information and support 12](#_Toc141283853)

[4.2 Recognition of symptoms 16](#_Toc141283854)

[4.3 Diagnostic tests 20](#_Toc141283855)

[4.4 Safety netting 25](#_Toc141283856)

[4.5 Cancer site-specific issues 28](#_Toc141283857)

[4.6 Additional areas 45](#_Toc141283858)

[Appendix: Suggestions from registered stakeholders 48](#_Toc141283859)

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.

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

Recommendations selected from the key development source are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development source referenced in this briefing paper is:

[Suspected cancer: recognition and referral. NICE guideline NG12](https://www.nice.org.uk/guidance/ng12) (2015, updated 2021).

The guideline was checked in June 2022 and an update on recommendations on colorectal cancer is planned when the update of [NICE's diagnostics guidance on quantitative faecal immunochemical tests to guide colorectal cancer pathway referral in primary care (DG30)](https://www.nice.org.uk/guidance/indevelopment/GID-DG10036) publishes (expected to publish November 2023).

1. Overview
   1. Focus of quality standard

This quality standard covers the recognition of and investigation for suspected cancer, and referral to specialist cancer services for adults, young people and children.

It will replace the existing [NICE quality standard for suspected cancer (QS124](https://www.nice.org.uk/guidance/qs124)).

* 1. Definition

Cancer 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. There are more than 200 different types of cancer, and each is diagnosed and treated in a particular way.

Changes to the body’s normal processes or unusual, unexplained symptoms can sometimes be an early sign of cancer (NHS website, [Cancer](https://www.nhs.uk/conditions/cancer/)).

* 1. Incidence and prevalence

Cancer has an enormous impact, both in terms of the number of people affected by it and the impact it has on people with cancer and those close to them. 384,339 new cases of cancer (excluding non-melanoma skin cancer) were diagnosed in the UK in 2019 - more than 1,000 new cases every day [Cancer Research UK’s Cancer in the UK: overview 2023](https://www.cancerresearchuk.org/health-professional/our-reports-and-publications#cancerUK), page 6).

Incidence rates in the UK have increased by 13% since the early 1990s. In 2020, in England, recorded incidence fell by 12% due to the impact of COVID-19 [Cancer Research UK’s Cancer in the UK: overview 2023](https://www.cancerresearchuk.org/health-professional/our-reports-and-publications#cancerUK), page 6).

The 2-week wait refers to people attending outpatient appointments within 2 weeks of an urgent referral by their GP for suspected cancer. At the start of the pandemic the number of 2-week wait referrals dropped by 60% compared to pre-pandemic levels. The number of patients on a 2-week wait suspected cancer pathway recovered within a few months of the start of the pandemic and by autumn 2022 had exceeded pre-pandemic levels ([Cancer Research UK’s Cancer in the UK: overview 2023](https://www.cancerresearchuk.org/health-professional/our-reports-and-publications#cancerUK), page 18).

[Cancer Research UK’s cancer statistics for the UK, Cancer incidence statistics and cancer risk statistics](https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk) and key findings of a summary of research into differences in cancer incidence by broad ethnic group in England 2013 to 2017 ([Delon C et al, 2022](https://www.nature.com/articles/s41416-022-01718-5)) report that:

* Breast, prostate, lung and bowel cancers together accounted for over half (53%) of all new cancer cases in the UK in 2016-2018.
* Incidence rates in England for all cancers combined are lower in people from Asian and Black ethnic backgrounds and in people from mixed or multiple ethnic backgrounds, compared with people from White ethnic backgrounds (2013 to 2017).
* A small number of cancer types are more common in certain ethnic groups compared to people from a White ethnic background, including myeloma, pancreatic and stomach cancer in people from a Black ethnic background, gallbladder cancer in people from Black or Asian ethnic backgrounds and prostate cancer in men from Black ethnic backgrounds.
* Each year, more than a third (36%) of all cancer cases in the UK are diagnosed in people aged 75 and over (2016-2018).

The [national qualitative deep dive report](https://www.ncpes.co.uk/2021-national-results/) (introduction, subsample: people with learning disabilities) for the 2021 Cancer Patient Experience Survey (CPES) based on analysis of qualitative feedback from 3 ‘open-ended’ questions about experiences of care commissioned by NHS England, highlights that:

* Overall, people with learning disabilities scored on average 8.01 out of 10 for overall care experienced. This is lower than the national average of 8.92 out of 10.
* Consistent with the findings of the national report, people with learning disabilities (including autistic people) reported negative experiences with the GP (including delayed diagnosis, poor access, the need for more information on cancer types, and waiting times for test results). Due to the small sample size, 2 additional themes for improvement unique to this group were identified: reasonable adjustments and sensitivity around diagnosis.

The national ambition is for 75% of cancers to be diagnosed at stages 1 and 2 ([NHS Long Term Plan](https://www.longtermplan.nhs.uk/)). [NHS Digital data](https://digital.nhs.uk/news/2022/cancers-diagnosed-at-stages-1-and-2) that has not been adjusted for case-mix highlight:

* In 2020 52% of cancers were diagnosed at stages 1 and 2 (54% in 2019).
* The unadjusted percentage diagnosed at stages 1 and 2 ranged from 19% (cancer of oesophagus (including cardia and gastroesophageal junction)) to 91% (cancer of the testis).
* 47% were diagnosed at stages 1 and 2 in the most deprived areas, compared to 55% in the least deprived areas.

[NHS Digital’s 2020 Cancer Registration Statistics](https://digital.nhs.uk/data-and-information/publications/statistical/cancer-registration-statistics/england-2020) highlight that:

* Male and female mortality rates in the 20% most deprived areas of England are at least 53% higher than for those in the 20% least deprived areas.
  1. Current service delivery and management

Data for the most recent edition of [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) covers 2006 to 2018 and shows that the 3 most common routes for diagnosis of malignant cancers (excluding non-melanoma skin cancer) continue to be:

* 2-week wait (urgent suspected cancer referral)
* GP referral (routine and urgent referrals where the patient was not referred under the 2-week wait referral route) although this has declined slightly since 2016.
* Emergency presentation, including A&E.

Trends in data in emergency presentation and other routes are shown below ([NHS Digital's Routes to diagnosis, interactive tool](https://www.cancerdata.nhs.uk/routestodiagnosis) – emergency presentations, counts and percentages.

Percentage of incident cancers (all malignant neoplasms excluding non-malignant skin cancer) diagnosed each year in England, split into each of the 8 Routes to Diagnosis), 2013 to 2018 (Routes to diagnosis – ‘demographics’):

A picture containing text, screenshot, line, plot

Description automatically generated

DCO: Death certificate only.

For some cancers, tests are carried out in primary care prior to a referral being made for further tests, such as the quantitative faecal immunochemical test (FIT) for colon cancer and blood tests including prostate specific antigen or cancer antigen (CA)125, for ovarian cancer.

Imaging investigations, such as chest X-Rays or ultrasound are generally available directly via referral from GPs through ‘direct access’ arrangements and ‘straight-to-test’ pathways. Under direct access arrangements, the primary care healthcare professional retains clinical responsibility throughout, including acting on the result. NICE NG12 recommends the following types of referral into cancer services:

|  |  |
| --- | --- |
| **Term in NG12** | **Explanation** |
| **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. |
| **Urgent referral (also known as the ‘2-week wait’** | To happen or be done before 2 weeks. An urgent referral means someone is referred to a cancer service within the national target in England and Wales for referral for suspected cancer, which is currently 2 weeks.  (National Cancer Waiting Times data measure: 14 days). |
| **Very urgent** | To happen within 48 hours. |

[The Office of Health Improvement and Disparities (OHID)’s Finger Tips Cancer Profile](https://fingertips.phe.org.uk/search/cancer)  data shows:

* over 2.6 million (2,663,105) 2-week referrals for suspected cancer (4,323 per 100,000 of the population) for 2020/21.
* only 6.8% of 2-week wait referrals resulted in a diagnosis of cancer.

The operational standard for achieving the 2-week wait is 93%. Annually, it has not been achieved consistently since 2017/2018 before which time it was generally met ([NHS England, Cancer Waiting Times National Time Series Oct 2009 - Mar 2023 with revisions](https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2022-23-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-march-2022-23-provisional/) (Q4 2022-23 statistical release: provider-based). Monthly data shows that performance has been below 90% from April 2021 (all cancers excluding symptomatic breast cancer) and consistently below 90% from November 2018 (with the exception of May and June 2020) for symptomatic breast cancer and that some variability exists between months. In March 2023:

* 83.9% of people were seen by a specialist within 2 weeks of an urgent referral for suspected cancer, for all cancers.
* 77.6% of people urgently referred for breast symptoms (where cancer was not initially suspected) were seen within 2 weeks of referral.
  1. Policy and service developments

The [2019 NHS Long Term Plan](https://www.longtermplan.nhs.uk/) sets an ambition to increase cancer survival rates by 2028. This is to be partially underpinned by increasing the percentage of cancers diagnosed at stages 1 or 2 to 75%.

Key service developments:

* The Faster Diagnosis Standard (FDS, patients receive a diagnosis or all-clear for cancer within 28 days of referral for testing and confirmation or exclusion of a diagnosis of cancer, with an operational standard of 75%, for all routes of diagnosis) was introduced in April 2021. This is part of the Faster Diagnosis Programme, which encompasses developing non-specific symptoms pathways and improving existing cancer pathways following urgent referrals to support greater efficiency through reducing health inequalities, early identification, timely referral, broad assessment of symptoms to enable effective triage, and coordinated testing for the timely diagnosis of cancer or otherwise [(FDS Framework](https://www.england.nhs.uk/cancer/faster-diagnosis/), sections 1.1 and 3.4).
* 7 [best practice timed pathways](https://www.england.nhs.uk/publication/rapid-cancer-diagnostic-and-assessment-pathways/) have been published to date; a hepato-pancreato-biliary pathway, covering pancreatic, liver, bile duct and gall bladder cancers is in development.
* Non-specific symptom pathways are being rolled out. Through national funding, all patients with non-specific symptoms will be referred via a non-specific symptoms pathway. There is flexibility around local implementation.
* The National Cancer Programme’s strategic approach to delivering faster diagnosis of cancer aligns with the community diagnostic centre programme [(FDS Framework](https://www.england.nhs.uk/cancer/faster-diagnosis/), section 3). These are one-stop shops delivering vital checks and scans including MRI and CT scans. Since their roll out began over 1 million checks and tests, including those for cancer, have been performed in over 90 centres. The NHS is committed to rolling out a network of up to 160 centres to deliver around 9 million additional tests and checks annually by 2025 ([NHS England, news item for 6 June 2022](https://www.england.nhs.uk/2022/06/one-million-checks-delivered-by-nhs-one-stop-shops/)).
* Monthly data shows that the FDS has been met once, in February 2023, although with the exception of 6 months (January; August to November inclusive 2022 and January 2023) it has been met in at least 70% of cases ([NHS England’s Cancer Waiting Times, National Time Series – Provider based, October 2009 to March 2023; Quarter 4 2008-9 to Q4 2022-23 – with revisions](https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2022-23-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-march-2022-23-provisional/)).
* All GP practices in England will be able to directly order CT scans, ultrasounds or brain MRIs for patients with concerning symptoms who fall outside the NG12 threshold for an urgent (suspected cancer) referral [(NHS England, news item 16 November 2022](https://www.england.nhs.uk/2022/11/nhs-gives-gp-teams-direct-access-to-tests-to-speed-up-cancer-diagnosis/)).

Primary Care Networks (PCNs) build on the core work of current primary care services and enable, at local level, greater provision of practice, personalised, coordinated and more integrated health and social care.

The [2023/24 Network Contract Directed Enhanced Service Specification](https://www.england.nhs.uk/gp/investment/gp-contract/network-contract-directed-enhanced-service-des/) for PCNs identifies reviewing referral practice for suspected (and recurrent cancer) as a priority for local improvement (8.5: early cancer diagnosis) with service requirements, relevant to this quality standard, around:

* FIT testing for suspected colorectal cancer.
* where available and appropriate, teledermatology (not mandatory for all referrals)
* proactive and opportunistic assessment for suspected cancer in population cohorts where referral rates have not recovered to pre-pandemic levels.
* reviewing use of non-specific symptoms pathways, including identifying opportunities and actions to increase ‘appropriate’ referral activity.
  1. Resource impact

We do not expect this quality standard to have a significant impact on resources. When NICE’s guideline on suspected cancer: recognition and referral was updated in December 2021, a resource impact statement was produced which noted that:

* the resource impact of implementing any single guideline recommendation will be less than £1 million per year in England (or £1,800 per 100,000 population) and

the resource impact of implementing the whole guideline in England will be less than £5 million per year (or £9,100 per 100,000 population).

This is because the recommendations had not changed significantly from the previous guideline.

The guideline includes recommendations on the symptoms and signs that warrant investigation and referral for suspected cancer.

Providers are NHS hospital trusts and primary care services.

1. Summary of suggestions
   1. Responses

In total 21 registered stakeholders responded to the 3-week engagement exercise.

* 11 stakeholders suggested areas
* 3 stakeholders had no comments

7 specialist committee members suggested areas

The responses have been summarised in table 1 for further consideration by the committee.

Table 1 Summary of suggested quality improvement areas

| Area for improvement | Stakeholders |
| --- | --- |
| **Information and support** | BCUK, NHSE-NCP, NHSE-LDAP, SCMs, TOC |
| **Recognition of symptoms**   * Awareness and response to symptoms * Non-specific symptoms | MDS UK PSG, NHSE-NCP, NHSE-LDAP, YLVC  NHSE-NCP, PCUK, SCMs |
| **Diagnostic tests**   * GP direct access to tests and scans * Test results | BCUK, NHSE-NCP, PCUK, SCMs  C52, MDS UK PSG, SCMS |
| **Safety netting** | BCUK, SCMs, TOC |
| **Cancer site-specific issues**   * Bladder cancer * Endometrial cancer * Lower GI and colorectal cancers * Lung cancer * Ovarian cancer * Pancreatic cancer * Prostate cancer * Skin cancer | SCM  SCMs  BCUK, NHSE-NCP, RPUK, SCMs  SCM  SCMs  PCUK  NHSE-NCP, SCM  NHSE-NCP, RPUK |
| **Additional areas**   * Central Nervous System & brain cancers * Diagnostics for MDS * Prevention * Referral to multidisciplinary team after diagnosis * Retinoblastoma guidance * Screening * Self-referral * Sensitivity and specificity of diagnostic tests | SCM  MDS UK PSG  ABS  SCM  BHNHST, CECT  NHSE-LDAP  C52  SCM |

Abbreviations:

* ABS, Association of Breast Surgery
* BCUK, Bowel Cancer UK
* BHNST, Barts Health NHS Trust
* C52, Cancer52
* CECT, Childhood Eye Cancer Trust
* MDS UK PSG, MDS (Myelodysplastic Syndrome) UK Patient Support Group
* NHS England:
  + NHSE-NCP, NHS Cancer Programme
  + NHSE-LDAP, National Learning Disability and Autism Programme
* PCUK, Pancreatic Cancer UK
* RPUK, Roche Products UK
* SCM, Specialist Committee Member
* TOC, Target Ovarian Cancer
* YLVC, Young Lives Versus Cancer

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

1. Suggested improvement areas

Section 4 presents a summary of the suggested improvement areas, with provisional recommendations that may support statement development and information on current UK practice.

* 1. Information and support

Stakeholders highlighted the importance of providing information to people presenting in primary care about suspected cancer referral and diagnosis, highlighting the following topics:

* Information about referral for suspected cancer.
* Importance of attending diagnostic appointments (primary, secondary care and other services).
* Reassurance: most people who are referred will not have a diagnosis of cancer.
* Benefits of early diagnosis
* What to expect of tests for investigation for suspected cancer and those which may follow.
* Sources of help and support, including signposting to trusted resources.

Stakeholders felt that providing information on these topics would help to encourage attendance at appointments, helping to reduce delays and non-attendance.

Stakeholders also suggested that following-up with people who do not attend urgent referral appointments is a quality improvement area, highlighting that administrative errors may contribute to non-attendance. Older people, people from more deprived areas and people with ‘difficult lives’ (such as complex social factors and comorbidities) were highlighted as important groups to focus on.

The importance of providing clear and consistent information was highlighted. Some stakeholders felt that providing written information about referral is a quality improvement area, but others highlighted that people (including their family or carers) could be better supported by communicating information in a range of formats; written information is not always appropriate for people in certain groups, including people with disabilities, including learning disabilities.

Stakeholders also felt that improving the experience of people with a learning disability and autistic people is a priority. The need for additional staff training and requirements of the [NHS Accessible Information Standard](https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/) and [2010 Equality Act](https://www.gov.uk/guidance/equality-act-2010-guidance) were also highlighted.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

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.

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).

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.

1.14.4 Give the person information on the possible diagnosis (both benign and malignant) in accordance with their wishes for information (see also NICE's guideline on patient experience in adult NHS services).

1.14.5 The information given to people with suspected cancer and their families and/or carers should cover, among other issues:

* where the person is being referred to
* how long they will have to wait for the appointment
* how to obtain further information about the type of cancer suspected or help before the specialist appointment
* what to expect from the service the person will be attending
* what type of tests may be carried out, and what will happen during diagnostic

procedures

* how long it will take to get a diagnosis or test results
* whether they can take someone with them to the appointment
* who to contact if they do not receive confirmation of an appointment
* other sources of support

1.14.6 Provide information that is appropriate for the person in terms of language, ability and culture, recognising the potential for different cultural meanings associated with the possibility of cancer.

1.14.7 Have information available in a variety of formats on both local and national sources of information and support for people who are being referred with suspected cancer.

1.4.10 When referring a person with suspected cancer to a specialist service, assess their need for continuing support while waiting for their referral appointment. This should include inviting the person to contact their healthcare professional again if they have more concerns or questions before they see a specialist.

1.16.5 Ensure local arrangements are in place to identify people who miss their appointments so that they can be followed up.

#### Published quality statements

[NICE's quality standard on suspected cancer (QS124):](https://www.nice.org.uk/guidance/qs124)

Statement 4 People with suspected cancer who are referred to a cancer service are given written information encouraging them to attend.

#### Current UK practice

Data tables for the [2021 Cancer Patient Experience Survey (CPES)](https://www.ncpes.co.uk/2021-national-results/) (responses from 59,352 people aged 16 and over with a confirmed diagnosis of cancer who were admitted to hospital as inpatients or were seen as day-cases for cancer-related treatment) highlight that of the respondents who had tests during the last 12 months that helped to diagnose their cancer (86.4%):

* 64% of 38,947 responses to the question reported that people felt that referral for diagnosis was explained in a way they could completely understand.
* Respondents ([data available via the interactive results display](https://www.ncpes.co.uk/interactive-results/)) were the least likely to say that their referral for diagnosis was explained in way they could completely understand:

* + in the 16-24 age group (50.0%)
  + people with a learning disability (51.6%).
  + in the Asian ethnic group (54.8%).
  + People with blindness or partial sight (55.8%)
* 93% of 47,007 responses to the question reported that people had received all the information they needed before tests were carried out and least likely to agree they had received all the information they needed:
  + in the 16-24 age group (86.0%).
  + if they had a learning disability (86.1%) or mental health condition (88.4%)

The [national deep-dive (qualitative) report for the 2021 CPES](https://www.ncpes.co.uk/2021-national-results/) question B ‘was there anything that could be improved?’ used individual analyses of national qualitative data to provide greater understanding of variation of care experienced by people in specific groups, including those living in the most deprived areas, from different ethnic groups, reporting a mental health condition, with learning disabilities and young people and adults aged 16 to 44. Findings in this area highlighted:

* a need for information on support or self-help groups.
* a need for information on waiting times for appointments.
* Access to interpreters and information that can be read by people experiencing language barriers.
* Need for reasonable adjustments for people with learning disabilities and autistic people, noting the need for ‘easy read’ information and additional support around sensory and communication needs.

### Issues for consideration

**For discussion:**

* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Recognition of symptoms

Awareness and response to symptoms

Stakeholders felt that improving GPs’ awareness of signs and symptoms of cancer is a quality improvement area.

They commented that access to decision support tools to support referral or requests for further diagnostic tests could help improve the quality of referrals. It was suggested that these should consist of algorithm-based tools, symptom reference guides using content from NG12 and requests for advice by GPs from consultants using the NHS e-referral system.

Stakeholders suggested that earlier recognition of signs and symptoms of cancer in children and young people among GPs and other healthcare professionals is an important area.

Stakeholders also commented that signs and symptoms may differ in people with learning disabilities and autistic people. Symptoms of cancer may be attributed to their autism or learning disability. They suggested lower thresholds for referral by GPs and accelerated access to diagnosis and treatment. People with learning disabilities and autistic people may experience difficulty in communicating physical pain and emotional distress. Stakeholders highlighted that making reasonable adjustment, as mandated by the [2010 Equality Act](https://www.gov.uk/guidance/equality-act-2010-guidance), are essential to enable symptoms and signs of cancer to be recognised in these populations to avoid delayed diagnosis.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

Recommendations organised by symptoms and findings of primary care investigations are provided in [NG12’s recommendations organised by symptoms and findings](https://www.nice.org.uk/guidance/ng12/chapter/Recommendations-organised-by-symptom-and-findings-of-primary-care-investigations#abdominal-symptoms) recommendations are contained within sections 1.1 to 1.12. There are a range of [NICE endorsed implementation tools and resources](https://www.nice.org.uk/guidance/ng12/resources) for NG12.

1.16.1 Take part in continuing education, peer review and other activities to improve and maintain clinical consulting, reasoning and diagnostic skills, in order to identify at an early stage people who may have cancer, and to communicate the possibility of cancer to the person.

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.

#### Current UK practice

The [2021 Cancer Patient Experience Survey (CPES)](https://www.ncpes.co.uk/interactive-results/) interactive results, national data tables highlight that, overall, 77.0% (29,023) of respondents agreed that they “only spoke to a primary professional once or twice before cancer diagnosis”. Of those, 55.4% of young people and adults aged 16 to 24 agreed, a significantly lower proportion than reported for other age groups. The proportion of people with a learning disability who agreed was significantly lower (147, 63.3%) than the overall score for all but one of the other long-term conditions (mental health conditions, 1,336 responses, 69.8%). The 2021 [Cancer Experience Patient Survey (CPES) for the under 16s (national summary)](https://public.tableau.com/app/profile/cpes.picker/viz/CYPCPES2021Dashboards/Guidance?publish=yes) interactive results shows that 63% of parents or carers reported that their child saw a GP once or twice before they were referred to hospital.

### Non-specific symptoms

Stakeholders felt that the current quality standard does not address people presenting with ‘non-specific symptoms’ or ‘non-site specific’ (signs and symptoms which do not fit clearly into a single ‘urgent cancer’ referral pathway (as specified in NG12), such as unexplained symptoms or those associated with a number of cancers. It was also noted that symptoms of some cancers may overlap (pancreatic, oesophageal and stomach cancers). They felt that referring people with these symptoms onto new non-specific symptom pathways which are being rolled out by NHS England is a quality improvement area. Stakeholders highlighted that minimum referral criteria and pre-referral filter tests should be used to make referrals. GPs ‘gut feeling’ is also a valid criteria for referral (alone or in combination with symptoms).

#### Selected recommendations

[NICE’s guideline on suspected cancer NG12:](https://www.nice.org.uk/guidance/ng12/)

1.13.1 Take into account the insight and knowledge of parents and carers when considering making a referral for suspected cancer in a child or young person. Consider referral for children if their parent or carer has persistent concern or anxiety about the child's symptoms, even if the symptoms are most likely to have a benign cause.

1.13.2 For people with unexplained weight loss, which is a symptom of several cancers including colorectal, gastro-oesophageal, lung, prostate, pancreatic and urological cancer:

* carry out an assessment for additional symptoms, signs or findings that may help to clarify which cancer is most likely **and**
* offer urgent investigation or a suspected cancer pathway referral (for an appointment within 2 weeks).

1.13.3 For people with unexplained appetite loss, which is a symptom of several cancers including lung, oesophageal, stomach, colorectal, pancreatic, bladder and renal cancer:

* carry out an assessment for additional symptoms, signs or findings that may help to clarify which cancer is most likely **and**
* offer urgent investigation or a suspected cancer pathway referral (for an appointment within 2 weeks).

1.13.4 For people with deep vein thrombosis, which is associated with several cancers including urogenital, breast, colorectal and lung cancer:

* carry out an assessment for additional symptoms, signs or findings that may help to clarify which cancer is most likely **and**
* consider urgent investigation or a suspected cancer pathway referral (for an appointment within 2 weeks).

#### Current UK practice

As part of work to support earlier diagnosis of cancer and to meet the Faster Diagnosis Standard, Cancer Alliances have been developing, since 2019, new pathways for patients with non-specific symptoms which may indicate cancer. It is planned that there will be full population coverage by the end of March 2024. This cohort of patients do not clearly fit the criteria for an urgent referral for suspected cancer. This cohort are triaged, have investigations and are safety netted regardless of age on these pathways. Only the referrer can withdraw or downgrade the referral; patients may be discharged back to their GP after triage and after they have been seen by a consultant (or member of their team) for the first time or at a diagnostic clinic or go 'straight-to-test’ in a consultant-led service (except for a blood test), if cancer is ruled out at that point. [NHS Cancer Programme Faster Diagnosis Standard Framework](https://www.england.nhs.uk/cancer/faster-diagnosis/) (2019, section 5).

Annex 1 in the [Faster Diagnosis Standard Framework](https://www.england.nhs.uk/cancer/faster-diagnosis/) defines referral criteria and core tests. Referral criteria include unexplained, constitutional symptoms and abnormal radiology and GP ‘gut instinct’.

A service evaluation by [Chapman et al (2021)](https://doi.org/10.3399/BJGP.2020.1108) of an urgent referral pathway for non-specific symptoms at 5 multidisciplinary diagnostic centre pilot projects in England between 1 December 2016 to 31 July 2018 used a common dataset. From 5,134 referrals, 25% of patients had 3 or more consultations with their GP before referral; 23% for the less common types of cancer and 28% for the common types.

Issues for consideration

**For discussion:**

* Awareness of symptoms:
  + We can’t have a statement which says ‘follow NICE guidance’ for awareness of symptoms. Site-specific improvement areas are highlighted in section 4.5.
  + We can’t prioritise a statement on GP training (awareness and recognition of symptoms suggestion).
  + Consulting with a specialist (1.16.2) is only a ‘consider’ recommendation in NG12.
* Non-specific symptoms
  + Would a focus on overlapping symptoms be helpful?
* What is the priority for improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Diagnostic tests

GP direct access to tests and scans

Stakeholders proposed that reducing variation in GP direct access to tests and scans for people with suspected cancer, to reduce time to diagnosis, is a quality improvement area. Some stakeholders supported retaining statement 1 in the current quality standard. They also commented on the importance of people accessing urgent direct access tests and scans within 2 weeks, noting that there is variation in availability and the time taken to perform them. They also commented that there may be a lack of clarity as to the optimum referral route (direct access, non-specific symptom pathways or site-specific pathways) when symptoms are non-specific (pancreatic cancer). Stakeholders also highlighted the recent expansion of direct access to diagnostic scans for investigations falling outside thresholds for triggering an urgent (2-week wait) suspected cancer referral.

Stakeholders felt that implementing best practice timed pathways would streamline the start of the suspected cancer pathway. They highlighted that pathways using a ‘straight-to-test’ model improve experience of care and support meeting the Faster Diagnosis Standard. In these pathways, 2-week wait suspected cancer referrals from GPs are triaged by consultants or cancer specialist nurses as appropriate and sent straight for diagnostic testing rather than sending them first to a hospital clinic ([Orchard P et al, 2020](http://dx.doi.org/10.1136/bmjqs-2019-009975), 467-468).

#### Selected recommendations

[NICE’s guideline on suspected cancer (N12):](https://www.nice.org.uk/guidance/ng12/)

1.2.1 Offer urgent, direct access (when a test is done and primary care retain clinical responsibility throughout, including acting on the result) upper gastrointestinal endoscopy (to be done 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.

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

* with dysphagia **or**
* aged 55 and over with weight loss and any of the following:

－ upper abdominal pain

－ reflux

－ dyspepsia.

There are ‘consider’ recommendations for very urgent direct access for bone sarcoma and soft tissue sarcoma in children and young people (1.11.2, 1.11.3, 1.11.6)

There are ‘consider’ recommendations for urgent direct access for the following cancer sites: pancreatic (1.2.5), gallbladder (1.2.10), liver (1.2.11), soft tissue sarcoma, endometrial (1.5.12), testicular cancer (1.6.8), brain and central nervous system cancer (1.9.1).

There are ‘consider recommendations’ for non-urgent direct access for the following cancer sites: oesophageal (1.2.2, 1.2.3) and stomach (1.2.8 and 1.2.9).

#### Published quality statements

[NICE's quality standard on suspected cancer (QS124):](https://www.nice.org.uk/guidance/qs124)

Statement 1 GPs have direct access to diagnostic endoscopy, ultrasound, MRI, X-ray and CT for people with suspected cancer.

Statement 2 People presenting in primary care with symptoms that suggest oesophageal or stomach cancer have an urgent direct access upper gastrointestinal endoscopy.

[NICE's quality standard on dyspepsia and gastro-oesophageal reflux disease in adults: investigation and management (QS96):](https://www.nice.org.uk/guidance/qs96)

Statement 2 Adults presenting with dyspepsia or reflux symptoms are referred for urgent direct access endoscopy to take place within 2 weeks if they have dysphagia, or are aged 55 and over with weight loss.

[NICE's quality standard on brain tumours (QS203):](https://www.nice.org.uk/guidance/qs203)

Statement 1 GPs have direct access to MRI for adults with suspected brain tumour.

#### Current UK practice

The [Diagnostic Imaging Dataset](https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/) is a monthly data collection covering data on diagnostic imaging tests carried out on NHS patients in England. It includes estimates of GP usage of direct access to key diagnostic tests for cancer. The [statistical commentary on most recent data (2022 to 2023; data from April 2022 is provisional)](https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/diagnostic-imaging-dataset-2022-23-data/) highlights that:

* 43.4 million imaging tests were reported in England from February 2022 to January 2023.
* In January 2023, GPs requested 29.5% of all tests that may have been used to diagnose or discount cancer under direct access arrangements.

The most frequently requested test by GPs was chest X-ray (197,000). The test with the highest proportion of GP referrals were ultrasounds that may be needed to diagnose ovarian cancer, 48% (46,845) of which were requested by GPs. The lowest proportion of referrals made by GPs was for brain MRI (13%, 8,745).

The commentary also highlights the median time between the date that the test was requested and the test was completed for all referral routes and GP direct access during this period. The median number of days between the date test being requested and the date completed is noticeably longer for GP direct access than overall for the following ultrasound tests in January 2023, for kidney or bladder and abdomen or pelvis (or both). The differences are smaller for brain MRI and chest or abdomen (or both) CT.

It should be noted however that data for all referrals includes tests on emergency admission and for inpatients which have shorter waits.

No current data or large scale national study published in the last 5 years has been identified around variation in access to direct access by GPs. However, NHS England’s (2022) [NHS England’s (2022) news item 'NHS gives GP teams direct access to tests to speed up cancer diagnosis'](https://wessexcanceralliance.nhs.uk/wp-content/uploads/2023/03/2.0-GP-Direct-Access-Guidance.pdf) highlights the continued roll-out (since July 2021) of Community Diagnostic Centres to boost the number of GP direct access tests that are available, to provide up to 3 million tests 2022-23 and up to 9 million per year by the end of 2025 to support earlier diagnosis.

Small-sale studies of the impact of straight-to-test (STT) pathways to diagnosis have been carried out for specific pathways, including:

* 6 hospital trusts across the East Midlands Clinical Network introduced a straight-to-test pathway ([Jones J A et al (2018](https://bmjopenquality.bmj.com/content/7/3/e000328.abstract)) which enables GPs to refer patients with suspected oesophageal or gastric cancer for immediate investigation, without the need to see a specialist first: 340 patients followed the STT pathway and 495 followed the traditional route. The number of tests performed were similar: an average of 7 days was saved from referral to treatment and 16 days from referral to diagnosis compared to a traditional pathway.
* An evaluation by [Thanapal MR et al (2021)](https://doi.org/10.1016/j.surge.2020.09.003) of 7 years’ experience (2012 to 2018) of a straight-to-test colonoscopy for colorectal cancer at Whittington Hospital (London) highlighted that the pathway took 25 days to obtain results compared to 40 days, shortening the cancer pathway by 3 weeks.

### Test results

Stakeholders felt that improving and reducing geographical variation in the timeliness of receiving test results, including those from tests and scans ordered using Direct Access arrangements, is a quality improvement area. They highlighted that the Faster Diagnosis Standard states that people with suspected cancer should not wait more than 28 days from referral to find out whether or not they have cancer. Other stakeholders highlighted that some people have waited 6 or more weeks for results of scans. They also commented that late results may result in lost opportunities for complex cases to be referred to specialist centres.

Stakeholders also highlighted the impact of poor reporting processes, including incomplete results, follow-up and notification of results on obtaining a diagnosis. Stakeholders also suggested interoperable systems could mitigate the risk of human error, enabling specialists to access accurate information. Stakeholders also highlighted the importance of supporting patients who receive unexpected test results.

Stakeholders commented that autistic people may experience increased levels of anxiety, relating specifically to intolerance of uncertainty, when awaiting test results. They highlighted that some autistic people, who experience alexithymia, may have different reactions when receiving test results than a health professional would expect. Stakeholders highlighted that making reasonable adjustment, as mandated by the [2010 Equality Act](https://www.gov.uk/guidance/equality-act-2010-guidance), is critical.

#### Selected recommendations

No recommendations identified.

#### Current UK practice

The statistical commentary for [Diagnostic Imaging Dataset](https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/) data from 2022/23 (provisional data from April 2022) highlights key findings and trends in data for the median number of days between the date of test and the date the test report is issued for groups of tests suitable for diagnosing cancer, for all referrals and GP Direct Access, January 2022 to January 2023:

* The median time for kidney or bladder ultrasound and abdomen or pelvis (or both) ultrasound was 0 days (same day reporting) for all referrals, including those made by a GP.
* The median time for reporting for chest or abdomen CT (or both) was slightly longer (generally 4 days) than for Chest X-Ray (typically 2 days for GP referral).
* There is generally little difference between the time for a test report for GP direct access and all referrals, although reporting periods were slightly longer for brain MRI.

Of around 86.4% of respondents to the [2021 CPES](https://www.ncpes.co.uk/2021-national-results/) who had tests to help them diagnose their cancer:

* 78.8% (of 49,718 responses to the question) who received a rest said the results were explained in a way they could completely understand.
  + Respondents:
    - in the 16-24 and 25-34 age groups were the least likely to report the results were explained in a way they could completely understand (between 66.7%, 165 responses and 66.5%, 471 responses).
    - in the 75-84 age group were most likely to say results were explained in a way they could completely understand (80.7%, 12,671 responses)
    - with a learning disability said that diagnostic test results were explained in a way they could completely understand (61.3%, 248 responses).
    - in the White ethnic group were most likely to report that results were explained in a way they could completely understand; people from Asian and Black ethnic groups were the least likely (below 70%, based on 1,252 and 749 responses respectively). Ethnicity for around 78.5% of respondents was ‘not given’ (3,323 responses).
* Overall 81.9% (of 49,536 responses for the question) felt that the length of time waiting for diagnosis test results was about right. However, the breakdown of tumour groups revealed that the score was significantly lower than the average for brain and CNS cancers.

The [national deep-dive (qualitative) report](https://www.ncpes.co.uk/2021-national-results/) highlighted the need for reasonable adjustments for people with learning disabilities and autistic people, noting the need for ‘easy read’ information and staff training on understanding additional support needs, sensory issues and communication difficulties.

Issues for consideration

**For discussion:**

* What is the key action that will lead to improvement?
* Should we keep statement 1 from the current QS?
* No recommendations were identified in NG12 for timeliness or completeness of test reports.
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Safety netting

Stakeholders felt that monitoring changes in the health of people at a higher risk of developing cancer due to a range of factors (age and ethnicity, genetic and other conditions) which may lead to cancer is a quality improvement area, to help support earlier diagnosis.

Stakeholders also suggested that people who experience persistent symptoms suggestive of a cancer but have had normal results should be identified for follow-up using a GP patient record system to maintain continuity across the diagnostic pathway and between multiple healthcare professionals.

Stakeholders suggested that following-up and acting on test results is a quality improvement area. Stakeholders felt that checks for rare and less common cancers during the course of diagnostic tests (including CT scans for lung cancer) for more prevalent cancers should be carried out.

Stakeholders suggested that giving patients advice on safety netting that communicates what it is and acknowledges their symptoms is a quality improvement area and that it should include a clear follow-up plan where a ‘watch and wait’ approach has been agreed. They also commented that people with learning disabilities and autistic people may experience difficulty in communicating physical pain and emotional distress. They also highlighted that making reasonable adjustment, as mandated by the 2010 Equality Act, is critical.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

1.14.8 Reassure people in the safety netting group (see recommendation 1.15.2)

who are concerned that they may have cancer that with their current

symptoms their risk of having cancer is low

1.14.9 Explain to people who are being offered safety netting (see

recommendation 1.15.2) which symptoms to look out for and when they

should return for re-evaluation. It may be appropriate to provide written

information.

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.

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.

[NICE’s guideline on familial breast cancer](https://www.nice.org.uk/guidance/cg164) (CG164):

1.6.1 Women at increased risk of breast cancer should be 'breast aware' in line with Department of Health advice for all women. **]**

There are recommendations on surveillance for women at low risk. Surveillance for women at high risk is run by [NHS Breast screening programme](https://www.gov.uk/topic/population-screening-programmes/breast).

#### UK current practice

No national data or large-scale published studies have been identified on monitoring people at a higher risk of cancer due to genetic or family history.

A small-scale study carried out in Oxfordshire ([Evans et al, 2018](https://bjgp.org/content/68/672/e505.short)) investigated how safety netting is carried out in primary care for potential cancer presentations. 25 qualified GPs, identified through purposive sampling, participated in interviews November 2016 to June 2017. Key findings were identified through thematic analysis:

* Safety netting considered a pervasive element of (good) clinical practice
* Lack of consensus as to a definition of safety netting, with conflicting views as to whether it included ordering tests and whether responsibility lies with the patient or the GP.
* Actively monitoring every patient would be impossible and needlessly create additional work and patient anxiety. Robust safety netting was felt to be unnecessary for patient groups the GP suspects are at a lower risk (but not no risk) of cancer or in whom cancer is not suspected.

Variation in practice was noted where there was low concern about cancer, especially in patients where it was not naturally expected (such as gastric symptoms in younger patients) and around the extent of documentation in patient records. The study also noted that locums had a different approach to risk, choosing to safety net more meticulously or use lower thresholds for referral so that they were followed up in their absence.

GPs suggested that they retained responsibility for patients they perceive to be at risk of cancer or unlikely to take responsibility for their own follow-up (including being unknown to the GP or are unable to engage with the diagnostic process). 10-minute consultations were felt to be a barrier to effective safety netting, especially where the patient presents with multiple problems.

Issues for consideration

**For discussion:**

* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Cancer site-specific issues

### Bladder cancer

A stakeholder highlighted that people aged over 60 with recurrent urinary tract infections who meet the NG12 criteria should be referred to reduce delayed diagnosis. Stakeholders commented that these symptoms are associated with longer times to diagnosis than other symptoms of possible urological cancers. They also commented that women experience a longer diagnostic interval than men.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

1.6.5 Consider non-urgent referral for bladder cancer in people aged 60 and

over with recurrent or persistent unexplained urinary tract infection.

[NICE’s guideline on urinary tract infection (recurrent): antimicrobial prescribing (NG112):](https://www.nice.org.uk/guidance/ng112)

1.1.4 (extract) Refer or seek specialist advice on further investigation and management

for:

* people with recurrent upper UTI
* people with recurrent lower UTI when the underlying cause is unknown

#### Published statements

[NICE's quality standard on urinary tract infections in adults (QS90):](https://www.nice.org.uk/guidance/qs90)

Statement 5 Men with a recurrent urinary tract infection (UTI), and women with a recurrent lower UTI where the cause is unknown or a recurrent upper UTI, are referred for specialist advice.

#### UK current practice

[Cancer Research UK Statistics](https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bladder-cancer#heading-Zero) highlight that in 2016 to 2018, bladder cancer was the eleventh most common cancer in the UK.

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) (by stage) shows that of cases of invasive bladder cancer diagnosed at stages 1 and 2; respectively:

* 47.3% and 28.4% were diagnosed via 2-week wait referrals.
* 45.4% and 21.1% were diagnosed through a GP referral.
* 20.3% of stage 4 diagnoses were made through emergency routes.

### Endometrial cancer

Stakeholders felt that referral criteria for endometrial cancer for women with post-menopausal bleeding who are taking HRT should be clarified. They commented that prescriptions for HRT have increased significantly. This has caused capacity issues in secondary care because bleeding while taking HRT is very common.

They also highlighted that local pathways may specify that GPs order an ultrasound for women with postmenopausal bleeding before doing a 2-week (urgent) referral for suspected cancer. Stakeholders felt that national thresholds on endometrial thickness are needed to avoid variation in interpretation of ultrasound results.

Stakeholders also suggested that women on HRT should be given advice on postmenopausal bleeding and when to seek help.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

1.5.10 Refer women using a suspected cancer pathway referral (for an appointment within 2 weeks) for endometrial cancer if they are aged 55 and over with post-menopausal bleeding (unexplained vaginal bleeding more than 12 months after menstruation has stopped because of the menopause).

1.5.11 Consider a suspected cancer pathway referral (for an appointment within

2 weeks) for endometrial cancer in women aged under 55 with

post-menopausal bleeding.

1.5.12 Consider a direct access ultrasound scan to assess for endometrial cancer in women aged 55 years and over with:

* Unexplained symptoms of vaginal discharge who:
  + Are presenting with these symptoms for the first time, **or**
  + Have thrombocytosis, or
  + Report haematuria, or
* visible haematuria, or
  + Low haemoglobin levels, or
  + Thrombocytosis, or
  + High blood glucose levels.

[NICE’s guideline on the menopause: diagnosis and management](https://www.nice.org.uk/guidance/ng23/chapter/Recommendations) (NG23):

1.4.22 Explain to women with a uterus that unscheduled vaginal bleeding is a common side effect of HRT within the first 3 months of treatment but should be reported at the 3-month review appointment, or promptly if it occurs after the first 3 months (see [recommendations on endometrial cancer in the NICE guideline on suspected cancer)](https://www.nice.org.uk/guidance/ng12).

#### Published quality statements

There are no NICE quality standards covering endometrial cancer.

#### UK current practice

The most common specific location for uterine cancers in the UK is the endometrium. In females, uterine cancer is the fourth most common cancer ([Cancer Research Statistics, 2016-2018 for uterine cancer](https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/uterine-cancer#heading-Zero)).

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) shows that of cases of cancer of the uterus diagnosed at stages 1 and 2, respectively:

* 72.8.3% and 6.8% were diagnosed via 2-week wait referrals.
* 68.2% and 5.5% were diagnosed through GP referrals.
* 22.8% of stage 4 diagnoses were made through emergency routes.

An online national questionnaire survey ([Idle SA et al, 2021](https://doi.org/10.1177/20533691211024415)) investigated views of members of the British Menopause Society on the management of patients with unscheduled bleeding on hormone replacement therapy (HRT). The study highlighted that:

* 51% (91/178) clinicians would investigate patients with unscheduled bleeding within 3 to 6 months of starting sequential HRT versus 47% for continuous combined HRT.
* Around 30% would investigate unscheduled bleeding continuing beyond 6 months in women on sequential or combined HRT; 10% would investigate after 3 for sequential HRT, 15% for combined.
* 50% (88/176) of clinicians requested assessments as urgent and around 25% each as 2-week a wait suspected cancer referral and a routine referral.

The [British Gynaecological Cancer Society (BGCS) Uterine Cancer Guidelines: Recommendations for Practice (2021)](https://www.bgcs.org.uk/professionals/guidelines-for-recent-publications/) (3.2.3) recommends a thickness of double-layer endometrial thickness measurements on transvaginal ultrasound with a cut off of ≥4 mm should be investigated.

Advice on bleeding: No published data or large-scale studies were identified.

### Lower GI and colorectal cancers

Suggestions focused on improving how the faecal immunochemical test (FIT) is used in primary care to support early diagnosis of colorectal cancer. Stakeholders also commented that it should be made more widely available. Specific suggestions focused on using it:

* before referral so that people at the highest risk can be prioritised for further testing and help reduce delayed diagnosis.
* to test those with symptoms of colorectal cancer; those with positive results should be referred onto the urgent lower gastrointestinal referral pathway.
* for safety netting (for lower-risk patients).
* to diagnose upper gastrointestinal cancers.

Some stakeholders suggested that QS124 statement 3 should be amended to align with the BSG/ACPGBI’s [joint guideline on FIT in patients with signs or symptoms of suspected colorectal cancer](https://gut.bmj.com/content/71/10/1939). This guideline recommends using FIT in primary care for patients presenting with all NG12 for suspected colorectal cancer symptoms (including rectal bleeding). [NICE DG30](https://www.nice.org.uk/guidance/DG30) recommends that FIT is used in people with unexplained symptoms who do not meet the criteria for a suspected cancer referral Stakeholders suggested that using FIT could reduce uncertainty over the referral in primary care for people whose symptoms meet the urgent referral criteria (as per NG12) but have a negative FIT result. It was also noted that NHS England supports adoption of the BSG/ACPGBI’s guideline ([NHS England's October 2022 letter on using FIT in the Lower GI pathway (primary care](https://www.england.nhs.uk/publication/supporting-the-use-of-faecal-immunochemical-testing/)).

It was also suggested that following-up with people who have not returned FIT samples, or where there is a problem with the sample, is a quality improvement area.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

1.3.1 Refer adults using a suspected cancer pathway referral (for an appointment within 2 weeks) for colorectal cancer if:

* they are aged 40 and over with unexplained weight loss and abdominal pain or
* they are aged 50 and over with unexplained rectal bleeding or
* they are aged 60 and over with:
  + iron-deficiency anaemia or
  + changes in their bowel habit, or

tests show occult blood in their faeces.

1.3.4 Offer testing with quantitative faecal immunochemical tests (see the [NICE diagnostics guidance on quantitative faecal immunochemical tests to guide referral for colorectal cancer in primary care](https://www.nice.org.uk/guidance/dg30)) to assess for colorectal cancer in adults without rectal bleeding who:

* are aged 50 and over with unexplained:
  + abdominal pain or
  + weight loss, or
* are aged under 60 with:
  + changes in their bowel habit, or
  + iron-deficiency anaemia, or

are aged 60 and over and have anaemia even in the absence of iron deficiency.

[NICE’s diagnostic guidance on quantitative faecal immunochemical tests to guide referral for colorectal cancer in primary care](https://www.nice.org.uk/guidance/dg30) (DG30):

1.1 The OC Sensor, HM-JACKarc and FOB Gold quantitative faecal immunochemical tests are recommended for adoption in primary care to guide referral for suspected colorectal cancer in people without rectal bleeding who have unexplained symptoms but do not meet the criteria for a suspected cancer pathway outlined in [NICE’s guideline on suspected cancer](https://www.nice.org.uk/guidance/ng12) (recommendation 1.3.4).

**Note**: DG30 is currently being updated and is due to publish in November 2023. The [final scope](https://www.nice.org.uk/guidance/gid-dg10036/documents/final-scope) indicates that FIT could impact non-urgent referral to gastroenterology services, colonoscopy, or both.

[BSG (NICE-accredited) in conjunction with the ACPGB's guideline on FIT in patients with signs or symptoms of suspected colorectal cancer](https://gut.bmj.com/content/71/10/1939):

1 We recommend that FIT should be used by primary care clinicians to prioritise patients with clinical features of CRC for referral for urgent investigation.

2. We recommend that a FIT threshold of fHb ≥10µg Hb/g should be used in primary care to select patients with lower GI symptoms for an urgent referral pathway for CRC investigation.

3 We recommend that patients should not be excluded from referral from primary care for symptoms on the basis of FIT testing alone.

4. We suggest that clinicians should follow-up patients with no FIT result to encourage them to return a sample or, where the kit has been lost or inadequately submitted, offer a further test.

5. We suggest that patients who decline to return a FIT test should be counselled that evaluation of their symptoms is incomplete, and be encouraged to complete their test

8 We recommend that some patients with symptoms of suspected CRC may be managed in primary care if fHb <10µg Hb/g, and provided appropriate safety-netting is in place.

9 We suggest that patients with an fHb <10µg Hb/g but with persistent and unexplained symptoms for whom the GP has ongoing clinical concern should be referred to secondary care for evaluation.

10 We recommend that safety-netting protocols should incorporate advice and strategies for the diagnosis of CRC and extracolonic cancer, as well as other serious gastro-intestinal conditions.

#### Published statements

[NICE’s quality standard on suspected cancer (QS124):](https://www.nice.org.uk/guidance/qs124)

Statement 3 Adults presenting in primary care with symptoms that suggest colorectal cancer, who do not meet the referral pathway criteria, have a test for blood in their faeces.

NICE’s quality standard on colorectal standard QS20 does not cover FIT testing.

#### UK current practice

[NHS England’s Implementing a colorectal cancer diagnostic pathway](https://www.england.nhs.uk/publication/rapid-cancer-diagnostic-and-assessment-pathways/) highlights that:

* Colorectal cancer is the fourth most common diagnosed cancer in England and the second most common cause of death.
* In 2019, only 37% of all colon cancers were diagnosed at an early stage.

The [2021 CPES interactive results for lower GI and colorectal tumour group](https://www.ncpes.co.uk/interactive-results/) show that 72.8% of people diagnosed with these cancers agreed that they only spoke once or twice to their primary care professional before their cancer diagnosis. This was below the overall score, across all tumour groups, 77%.

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) shows that of cases of cases of colorectal cancer diagnosed at stages 1 and 2, respectively:

* 16.2% and 26.5% were diagnosed via 2-week wait referrals.
* 21.4% and 21.3% were diagnosed through GP referrals.
* 35.4% of stage 4 diagnoses were made through emergency routes.

The [National Bowel Cancer Audit’s annual report for 2022](https://www.nboca.org.uk/reports/annual-report-2022/) includes patients diagnosed with bowel cancer in England and Wales between 1 April 2020 and 31 March 2021 and patients diagnosed between 1 April 2019 and 21 March 2020 who underwent a major resection after 31 March 2020. The report highlights that the proportion of patients presenting via different pathways varies according to Cancer Alliance:

* GP referrals range from 44% to 69%. A total of 15,273 were referred by their GP.
* Emergency admissions (5,896) ranged from 14% to 30% and were highest among people age 60 to 74 (30.4%, 1,794/5,896)

A national survey of general practitioners ([Von Wagner et al, 2019](https://bmjopen.bmj.com/content/9/4/e025737)) assessed awareness of NICE’s DG30 in primary care 6 months after publication. A total of 1,024 GPs completed the survey. They found that 432/1024 (42%) were aware of the recommendations in NICE’s DG30 but only 102 (10%) GPs had used it to guide their referrals.

No national data or large-scale published studies have been identified around using FIT for safety-netting high or low-risk patients.

The [Impact and Innovation Fund indicator CAN-01](https://www.england.nhs.uk/primary-care/primary-care-networks/network-contract-des/iif/) measures the percentage of lower gastrointestinal 2-week wait cancer referrals accompanied by a FIT result, with the result recorded either in the 21 days leading up to the referral, or in the 14 days after the referral. Data for March 2023 (the most recent) shows achievement of 68.8%. Achievement excludes people who declined the test or there was no indication for offering the test. [2023/24 priorities and operational planning guidance (section 1E)](https://www.england.nhs.uk/publication/2023-24-priorities-and-operational-planning-guidance/) highlights that a key action is for at least 80% of Faster Diagnosis Standard lower gastrointestinal referrals are accompanied by a FIT result.

### Lung cancer

A stakeholder suggested that low-dose CT should be used in preference to chest X-Ray, particularly in people with a higher risk of lung cancer. They highlighted that GP access to low-dose CT is being commissioned locally and suggested that it should be made available more widely. They commented that low-dose CT is more effective for ruling out a diagnosis of lung cancer in certain presentations.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

* + 1. Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for lung cancer if they:
* have chest X-ray findings that suggest lung cancer **or**
* are aged 40 and over with unexplained haemoptysis.

1.1.2 Offer an urgent chest X-ray (to be done within 2 weeks) to assess for lung cancer in people aged 40 and over if they have 2 or more of the following unexplained symptoms, or if they have ever smoked and have:

* cough
* fatigue
* shortness of breath
* chest pain
* weight loss
* appetite loss.

#### Published quality statements

There is a [NICE quality standard on lung cancer (QS17)](https://www.nice.org.uk/guidance/qs17) but there is currently no statement on X-Ray or use of CT.

#### UK current practice

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) shows that of cases of cancer of the lung, trachea and bronchus diagnosed at stages 1 and 2, respectively:

* 16.6% and 9.3% were diagnosed via 2-week wait referrals.
* 28.9% and 8.8% were diagnosed through GP referrals.61.6% of stage 4 diagnoses were made through emergency routes

[The National Lung Cancer Audit’s State of the nation report 2023](https://www.lungcanceraudit.org.uk/reports/nlca-state-of-the-nation-report-2023/) highlights that of 34,478 patients diagnosed in England in 2021 and 2020, t35% were diagnosed via emergency presentation. This is an increase from 31% in 2019. The number of lung cancer cases diagnosed during COVID-19 (2020) fell from 33,091 in 2019 to 31,371 in 2020 but in 2021 had returned to pre-pandemic levels.

[Price S et al (2020)](https://doi.org/10.1016/j.canep.2020.101805) investigated trends in time to diagnosis before and after NICE’s guideline on suspected cancer was updated (NG12, 2015). Records from more than 600 UK GP practices (of which 389 linked to National Cancer Registration Service records) were analysed for adults with incident myeloma, breast, bladder, colorectal, lung, oesophageal, ovarian, pancreatic, prostate, stomach or uterine cancer [diagnosed] 1 January 2006 to 31 December 2017. The study highlighted that lung cancer had the longest median diagnostic interval (139.5 days) and the broadest range of symptoms (Table 4, 50th centile value for “New-NICE”).

A low-dose CT scan following initial assessment of people at higher risk is recommended by the [National Screening Programm](https://view-health-screening-recommendations.service.gov.uk/lung-cancer/)e. Screening is beyond the remit of the quality standard.

### Ovarian cancer

Stakeholders suggested that broader referral criteria (either for diagnostic investigations or review by a specialist) should be recommended for ovarian cancer because the symptoms specified in NG12 are associated with presentations of late-stage ovarian cancer. They also queried whether the positive predictive value underpinning the referral criteria (3%; see [NG12, context, page 94](https://www.nice.org.uk/guidance/ng12)) applies to all gynaecological cancers. The stakeholder suggested that it should be reduced for ovarian cancer.

It was suggested that referral criteria used in NICE-accredited guidelines should be used so that women with an abnormal ovarian ultrasound result are referred to a specialist. Stakeholders also commented that many GPs do not feel confident when interpreting ultrasound results for identification of ovarian lesions.

Stakeholders suggested that a raised CA125 result but a normal ultrasound scan should prompt assessment and investigation for other types of cancers (or other conditions).

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

1.5.1 Make an urgent referral to a gynaecological cancer service if physical

examination identifies ascites and/or a pelvic or abdominal mass (which

is not obviously uterine fibroids).

1.5.2 Carry out tests in primary care (see recommendations 1.5.6 to 1.5.9) if a

woman (especially if aged 50 or over) reports having any of the following

symptoms on a persistent or frequent basis – particularly more than

12 times per month:

* persistent abdominal distension (women often refer to this as 'bloating')
* feeling full (early satiety) and/or loss of appetite
* pelvic or abdominal pain
* increased urinary urgency and/or frequency

1.5.3 Consider carrying out tests in primary care (see recommendations 1.5.6 to 1.5.9) if a woman reports [unexplained](https://www.nice.org.uk/guidance/ng12/resources/suspected-cancer-recognition-and-referral-pdf-1837268071621) weight loss, fatigue or changes in bowel habit.

1.5.4 Advise any woman who is not suspected of having ovarian cancer to

return to her GP if her symptoms become more frequent and/or

persistent.

1.5.5 Carry out appropriate tests for ovarian cancer (see recommendations

1.5.6 to 1.5.9) in any woman aged 50 or over who has experienced

symptoms within the last 12 months that suggest irritable bowel

syndrome (IBS), because IBS rarely presents for the first time in women

of this age.).

1.5.6 Measure serum CA125 in primary care in women with symptoms that

suggest ovarian cancer (see recommendations 1.5.1 to 1.5.5).

1.5.7 If serum CA125 is 35 IU/ml or greater, arrange an ultrasound scan of the

abdomen and pelvis.

1.5.8 f the ultrasound suggests ovarian cancer, make an urgent referral to a

gynaecological cancer service.

1.5.9 For any woman who has normal serum CA125 (less than 35 IU/ml), or

CA125 of 35 IU/ml or greater but a normal ultrasound:

* assess her carefully for other clinical causes of her symptoms and investigate if appropriate
* if no other clinical cause is apparent, advise her to return to her GP if her symptoms become more frequent and/or persistent.

[NICE Clinical Knowledge Summary on ovarian cancer:](https://cks.nice.org.uk/topics/ovarian-cancer/diagnosis/when-to-suspect-ovarian-cancer/)

When should I suspect ovarian cancer? (extract)

Other symptoms of ovarian cancer that may be present include:

* Abnormal or postmenopausal including.
* Gastrointestinal symptoms, such as dyspepsia, nausea, or bowel obstruction.
* Shortness of breath (due to pleural effusion).

#### Published statements

[NICE’s quality standard on ovarian cancer (QS18):](https://www.nice.org.uk/guidance/qs18)

Statement 1 Women aged 50 years or over reporting one or more symptoms occurring persistently or frequently that suggest ovarian cancer are offered a CA125 test.

Statement 2 Women with raised CA125 have an ultrasound of their abdomen and pelvis within 2 weeks of receiving the CA125 test results.

#### UK Current practice

[Cancer Research UK statistics](https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer#heading-Zero) highlight that ovarian cancer is the sixth most common cancer in the UK (2016 to 2018).

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) shows that of cases of cancer of the ovary, fallopian tube and primary peritoneal carcinomas (including borderline) diagnosed at stages 1 and 2, respectively:

* 27.2.2% and 7.1% were diagnosed via the 2-week wait.
* 41.5% and 5.3% were diagnosed through GP referral.30.0% of stage 4 diagnoses were made through emergency routes.

[Price S et al (2020)](https://doi.org/10.1016/j.canep.2020.101805) investigated trends in time to diagnosis before and after NICE’s guideline on suspected cancer was updated (NG12, 2015). Records from more than 600 UK GP practices (of which 389 linked to National Cancer Registration Service records) were analysed for adults with incident myeloma, breast, bladder, colorectal, lung, oesophageal, ovarian, pancreatic, prostate, stomach or uterine cancer [diagnosed] 1 January 2006 to 31 December 2017. The study highlights that:

* Raised CA125 was the second most coded feature for ovarian cancer (12.9%); abdominal pain was the most common (34.7%),
* The median diagnostic interval was 56 days (based on the updated NICE guideline).

[NHS England’s (2023) Implementing a timed ovarian cancer diagnostic pathway](https://www.england.nhs.uk/publication/rapid-cancer-diagnostic-and-assessment-pathways/) highlights that:

* In 2018, patients with ovarian cancer had some of the longest intervals between referral and commencement of treatment among all cancers in England.
* This varied by cancer alliance with a range of 59 to 88 median days.

No published data or national studies were identified on how confident GPs feel to interpret ultrasound.

### Pancreatic cancer

A stakeholder suggested that rapid access to a CT scan on first presentation of jaundice in people age over 40 would support a faster and earlier diagnosis. They commented that pathways vary; in some areas ultrasound is offered instead of a CT scan.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

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.

[NICE’s guideline on pancreatic cancer (NG85](https://www.nice.org.uk/guidance/ng85)):

* + 1. For people with obstructive jaundice and suspected pancreatic cancer, offer a pancreatic protocol CT scan before draining the bile duct.

[RCR (NICE-accredited): iRefer: making the best use of clinical radiology (8th edition, 2017), Pancreatic cancer (CA11):](https://www.irefer.org.uk/)

CT or ultrasound: Choice of diagnostic technique depends on local expertise and the patient’s habitus. CT is more sensitive and reliable for visualising the whole pancreas, especially large patients, and the investigation of choice. Ultrasound is of particular value in thin patients presenting with jaundice. Where available, endoscopic ultrasound can be used to identify small lesions, problem-solving and for guiding aspirational biopsy.

#### Published quality statements

There is a [NICE quality standard on pancreatic cancer (QS177)](https://www.nice.org.uk/guidance/qs177). It does not cover recognition, referral or initial diagnostic tests.

#### UK current practice

[Cancer Research UK’s statistics on pancreatic cancer](https://www.cancerresearchuk.org/about-cancer/pancreatic-cancer) highlight that it is the tenth most common cancer in the UK, with around 10,500 people diagnosed annually.

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) shows that of cases of cancer of the pancreas diagnosed at stages 1 and 2, respectively:

* 7.5% and 10.0% were diagnosed via the 2-week wait.
* 10.1% and 10.7% were diagnosed through GP referral.53.5% of stage 4 diagnoses were made through emergency routes

[Price S et al (2020)](https://doi.org/10.1016/j.canep.2020.101805) investigated trends in time to diagnosis before and after NICE’s guideline on suspected cancer was updated (NG12, 2015). Records from more than 600 UK GP practices (of which 389 linked to National Cancer Registration Service records) were analysed for adults with incident myeloma, breast, bladder, colorectal, lung, oesophageal, ovarian, pancreatic, prostate, stomach or uterine cancer [diagnosed] 1 January 2006 to 31 December 2017. The study highlights that:

* Pancreatic cancer was characterised by jaundice in 15.2% of cases; and more commonly by abdominal pain (32.8%) and diabetes (22.0%) (Table 4, 50th centile value for “New-NICE”).
* Median diagnostic interval using NG12 was 126 days.

[NHS England’s report on waiting times for suspected and diagnosed cancer patients](https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/cwt-annual-reports/cancer-waiting-times-annual-report-2020-21/) showed that in 2020 to 2021, 84.9% of patients with suspected upper GI cancer were seen within 14 days. The operational standard is that 93% of all patients should be seen within 14 days.

No current practice data or published studies on rapid access to CT scan on first presentation of jaundice was identified.

### Prostate cancer

Stakeholders suggested the following as quality improvement areas:

* Reduce variation in management of asymptomatic (or early) presentation with slightly raised prostate-specific antigen (PSA) levels; differing thresholds are used and some consultants request repeat testing if PSA is <10 even within a single trust.
* Clinical capacity to support multiparametric MRIs before local anaesthetic transperineally biopsy to reduce the need for biopsy and associated risks.

#### Selected recommendations

[NICE’s guideline on suspected cancer (NG12):](https://www.nice.org.uk/guidance/ng12/)

1.6.2 Consider a prostate-specific antigen (PSA) test and digital rectal examination to assess for prostate cancer in people with:

* any lower urinary tract symptoms, such as nocturia, urinary frequency, hesitancy, urgency or retention **or**
* erectile dysfunction **or**
* visible haematuria.

1.6.3 Consider referring people with possible symptoms of prostate cancer, as specified in recommendation 1.6.2, using a suspected cancer pathway referral (for an appointment within 2 weeks) for prostate cancer if their PSA levels are above the threshold for their age in table 1. Take into account the person's preferences and any comorbidities when making the decision.

Table 1: Age-specific PSA thresholds for people with possible symptoms of prostate cancer

|  |  |
| --- | --- |
| **Age (years)** | **Prostate-specific antigen threshold (micrograms/litre)** |
| Below 40 | Use clinical judgement |
| 40 to 49 | More than 2.5 |
| 50 to 59 | More than 3.5 |
| 60 to 69 | More than 4.5 |
| 70 to 79 | More than 6.5 |
| Above 79 | Use clinical judgement |

[NICE’s guideline on prostate cancer (NG131):](https://www.nice.org.uk/guidance/ng12/)

1.2.2 Offer multiparametric MRI as the first-line investigation for people with suspected clinically localised prostate cancer. Report the results using a 5‑point Likert scale.

1.2.3 Offer multiparametric MRI-influenced prostate biopsy to people whose Likert score is 3 or more.

1.2.6 (extract) Help people decide whether to have an MRI or prostate biopsy by discussing: …. Do not automatically offer a prostate biopsy on the basis of serum PSA level alone.

#### Published quality statements

There is a [NICE quality standard on prostate cancer (QS91)](https://www.nice.org.uk/guidance/qs91). It does not cover recognition, referral or initial diagnostic tests.

#### UK current practice

The [National Prostate Cancer Audit’s annual report for 2022](https://www.npca.org.uk/reports/npca-annual-report-2022/) presents results for men diagnosed with, or treated for, prostate cancer between 1st April 2020 and 31st March 2021 in England and Wales. The report highlights that:

* Based on available staging data (for England), 35% were diagnosed with stage 1 prostate cancer and 15% with stage 2.
* The proportion of men presenting with metastatic disease in England and Wales was 17% (an increase from 13% on the previous year).

2018 data from the [Routes to Diagnosis study](https://www.cancerdata.nhs.uk/) shows that of cases of cancer of the prostate diagnosed at stages 1 and 2, respectively:

* 33.0% and 14.0% were diagnosed via 2-week wait referrals.
* 44.5% and 15.5% were diagnosed through GP referrals.49.4% of stage 4 diagnoses were made through emergency routes.

[NHS England’s Implementing a timed prostate cancer diagnostic pathway](https://www.england.nhs.uk/publication/rapid-cancer-diagnostic-and-assessment-pathways/) highlights that:

* In 2019 only 42% of prostate cancers were diagnosed at an early stage (stages 1 and 2) and that the rate varied by CCG with a range of 23% to 66%.
* A PSA of >3 ng [sic]/ml should be used as a referral threshold for men aged 50 to 69.

A survey using information from Freedom of Information (FOI) requests submitted by Prostate Cancer UK (PCUK) and the British Society of Urogenital Radiology in 2016 and in 2018 (by PCUK) investigated whether use of mpMRI had increased during the time between the 2 requests ([Davies C et al 2019](https://doi.org/10.1016/j.crad.2019.09.129)). The survey also investigated barriers to its use. Findings highlighted that:

* In 2018 86% of UK areas reported they provided some form of MRI before biopsy, with 56% reporting using mpMRI. There was geographical variation across the UK nations, but only 10/124 of trusts in England stated they did not make it available before biopsy in 2018.
* Eligibility criteria for pre-biopsy MRI varied, with the most common criterion being fitness for radical surgery (34% of areas reported restrictive criteria).
* Imaging practice and reporting showed variation:
  + some areas performed scans without dynamic contrast enhancement (DCE) and used the findings to guide referral decisions for biopsy (Note: [NG131](https://www.nice.org.uk/guidance/ng131), terms used in this guideline, states that mpMRI uses dynamic contrast-enhanced imaging).
  + 19 areas reported using a Likert scale (Note: the Likert scale is recommended by NICE) but 88 areas used a different system.

Barriers to implementation were reported to include the need to follow regional Cancer Network guidelines, scanner capacity and staffing levels. A limitation of the study was that not all areas answered every question, particularly around barriers to implementation as this was sometimes felt to lie outside the scope of the FOI request.

### Skin cancer

Stakeholders suggested that remote assessment of skin cancer using imaging (teledermatology) can support a faster diagnosis, manage high volumes of referral, reduce in-person hospital and outpatient attendance. They suggested that it is ideally delivered in primary care hubs or community diagnostic centres.

#### Selected recommendations

[NICE’s guideline on suspected cancer: recognition and referral](https://www.nice.org.uk/guidance/ng12) (NG12):

1.7.1 Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for melanoma if they have a suspicious pigmented skin lesion with a weighted 7‑point checklist score of 3 or more.

1.7.2 Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) if dermoscopy suggests melanoma of the skin.

#### Current quality statements

[NICE’s quality standard for skin cancer](https://www.nice.org.uk/guidance/qs130) (QS130):

Statement 3 People with suspected malignant melanoma are referred using a suspected cancer pathway for an appointment within 2 weeks.

Statement 4 People with pigmented skin lesions undergoing a specialist assessment have the lesions examined using dermoscopy.

Note: An update of QS130 is in development (due to publish in December 2023) and the above statements are expected to be reviewed.

#### Current UK practice

The [NHS England guidance for local health and care systems on implementing a timed skin cancer diagnostic pathway](https://www.england.nhs.uk/publication/rapid-cancer-diagnostic-and-assessment-pathways/) (2022) reported that in

* Skin cancer is the most common cause of cancer in England.
* In 2018 the variation between cancer alliances between time from referral to treatment from skin cancers (excluding basal cell carcinoma, soft tissue sarcoma and lymphoma) was 51 to 77.5 median days.

A [survey of dermoscopy use in UK primary care by GPs with a specialist interest in dermatology](https://onlinelibrary.wiley.com/doi/10.1111/jdv.15614) (Jones et al 2019) showed that 96.8% of respondents (February 2018) with access to a dermatoscope used it regularly when reviewing pigmented skin lesions. Its use was more common among GPs who had worked longer in primary care and had experience of secondary care dermatology. 91.0% had undertaken training in dermoscopy, although this was variable in length and modality. This survey also reported that 70.4% of respondents did not use teledermatology as part of the 2 week wait referral pathway for suspicious pigmented skin lesions. 205 responses from an online survey of members of the Primary Care Dermatology Society were analysed.

The [Getting it Right First Time Programme National Specialty Report for Dermatology](https://gettingitrightfirsttime.co.uk/girft-reports/) (2021) reported wide variation in access to teledermatology:

* 30% of trusts said that their local teledermatology services were adequately and safely integrated with their services
* 52% of trusts said that their local teledermatology services were not adequately and safely integrated with their services

18% of the 117 departments who responded had no local teledermatology service at all

Resource impact

The resource impact assessment for updated guideline NG12 did not identify any areas of significant resource impact (>£1 million in England each year) due to the low impact of changes made.

Recommendation 1.6.3 in updated guideline NG12 states consider referring people using a suspected cancer pathway referral (for an appointment within 2 weeks) for prostate cancer if their PSA levels are above the threshold for their age. Age-specific PSA thresholds are already established in current practice, however as there are regional variations in practice (particularly in the 50 and 69 age range), the age-specific PSA thresholds have now been clearly defined.

Issues for consideration

**For discussion:**

* Which, if any, site-specific priorities should be included in this quality standard?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. 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 need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the Advisory Committee meeting.

Summary of information available for additional areas

| Suggested area for improvement | Within remit of NICE QS | In scope | Guideline recs | Relevant  existing QS |
| --- | --- | --- | --- | --- |
| Central nervous system and brain cancers | No | Yes | Yes | QS203 (S 1) |
| Diagnostics for MDS | Yes | Yes | No | No |
| Prevention | Yes | No | Yes | Yes |
| Referral to multidisciplinary team after diagnosis | Yes | No | Yes | Yes (site-specific) |
| Retinoblastoma guidance | No | Yes | Yes | Yes |
| Screening | Yes | Yes | No | Yes |
| Self-referral | No | Yes | No | No |
| Sensitivity and specificity of diagnostic tests | No | No | No | No |

### Central Nervous System and brain cancers

It was suggested that the wording of NG12 recommendation 1.9.1 (‘Consider an urgent, direct access, MRI scan of the brain (or CT scan if MRI is contraindicated; to be done within 2 weeks) to assess for brain or central nervous system cancer (CNS) in adults with progressive, sub-acute loss of central neurological function’ is difficult for GPs to interpret. We will pass this feedback to our colleagues in the Centre for Guidelines.

### Diagnostics for MDS

MDS refers to myelodysplastic syndrome, which is a rare type of blood cancer where people lack enough healthy blood cells ([NHS website](https://www.nhs.uk/conditions/myelodysplasia/), Myelodysplastic syndrome (myelodysplasia)). Stakeholders suggested that improving diagnostics for this population is a priority. They highlighted that development of alternatives to bone marrow biopsy were important (in particular, peripheral blood tests), especially for elderly or frail people who cannot have a biopsy to have access diagnostic testing.

This area has not been progressed because NICE or NICE-accredited guidance to support the suggestion of improved diagnostic testing as an alternative to bone marrow biopsy has not been identified. The guidance that is available is not suitable as a development source for a quality standard; [British Society for Haematology (2021) guidelines for the diagnosis and evaluation of prognosis of adult myelodysplastic syndromes](https://doi.org/10.1111/bjh.17621) states that clinical monitoring (genetic testing on blood film) should be ‘considered’ if a patient is not fit for invasive investigations such as bone marrow aspirate and trephine, and that “sensitivity is highest on bone marrow, but can usefully be performed on peripheral blood in situations in which bone marrow biopsy is impractical or undesirable (provided that circulating myeloid cells are present).”

### Prevention

Prevention of cancer areas through positive changes to lifestyle was suggested as a quality improvement area. This area is out of scope for this quality standard, which focuses on recognition of symptoms and referral for suspected cancer.

### Referral to multidisciplinary team after diagnosis

Onward referral to a cancer multidisciplinary team (MDT) from primary care was suggested as a quality improvement area.

This area is outside the scope of this quality standard because it relates to care after diagnosis of cancer. The scope of this quality standard is recognition and referral of suspected cancer.

### Retinoblastoma guidance

Stakeholders proposed that wording to the recommendations about referral of children and young people for retinoblastoma should be amended (in NG12, ‘Consider urgent referral (for an appointment within 2 weeks) for ophthalmological assessment for retinoblastoma in children with an absent red reflex. If there is new-onset squint that occurs together with an absent red reflex, see the recommendation on new-onset squint with loss of red reflex in NICE's guideline on suspected neurological conditions’). They commented that referring to ‘an absent red reflux’ does not reflect that the healthy reflex in children from minority ethnic backgrounds may be orange or pale, leading to over-referral and over-investigation of healthy children from these groups. This is an additional area because it is a comment on NICE guidance. We will pass this feedback to our colleagues in the Centre for Guidelines.

### Screening

It was suggested that age thresholds for screening programmes, including for colorectal cancer (bowel screening) could be lowered to mitigate late recognition in people with learning disabilities. Screening for cancer is in the remit of the National screening committee and as such, is out of scope for this quality standard.

### Self-referral

Stakeholders suggested that people should be able to self-refer for CT, MRI or ultrasound scans if they have concerning symptoms that have not been diagnosed by their GP.

Establishing self-referral routes, such as cancer hotlines, has been identified as part of an objective for defining and delivering a locally agreed set of pathway innovations and improvements to support the [National Cancer Programme’s Faster Diagnosis Standard](https://www.england.nhs.uk/cancer/faster-diagnosis/)and the Government’s [10-Year Cancer Plan](https://www.gov.uk/government/consultations/10-year-cancer-plan-call-for-evidence/10-year-cancer-plan-call-for-evidence#the-10-year-cancer-plan-for-england), 2022 to 2032. No recommendations in NICE or NICE-accredited guidance have been identified**.**

### Sensitivity and specificity of diagnostic tests

Stakeholders queried the underpinning data for NHS England’s approach to using negative predictive value in relation to diagnostic tests. This is because predictive values depend on the prevalence of the condition been tested: low prevalence results in a low positive predictive value and a high negative predictive value and vice versa.

Reviewing sensitivity and specificity of diagnostic testing is outside the scope of this quality standard. At NICE, this work is in the remit of the Centre for Health Technology Evaluation. We will pass this comment to them..

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# Appendix: Suggestions from registered stakeholders

| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
| 1 | Bowel Cancer UK | **Information and support**  Tackling inequalities | Tackling inequalities in colorectal cancer diagnosis requires a number of interventions across the diagnostic pathway.  Primary and secondary care must ensure information is appropriate and accessible for each patient, taking a person-centred approach to referral and diagnosis.  A Bowel Cancer UK [factsheet for referral of patients under 50](https://bowelcancerorguk.s3.amazonaws.com/Publications/A%20guide%20for%20GPs_ReviewedNovember2020.pdf) has already been endorsed by NICE for use by GPs.  Patient information that is accessible for those with disabilities, impairments or sensory loss, as well as for those whose first language is not English, should be made available. | NHS England’s [‘Accessible Information: Specification v.1.1’](https://www.england.nhs.uk/wp-content/uploads/2017/08/accessilbe-info-specification-v1-1.pdf)   “Promoting equality and addressing health inequalities are at the heart of NHS England’s values. Throughout the development of the policies and processes cited in this document, we have:   • had due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and   • had regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.” |
| 2 | Bowel Cancer UK | **Information and support**  Encouraging attendance at cancer services/Early diagnosis | It is vital for early diagnosis of colorectal cancer that patients are aware of the importance of attending diagnostic appointments.  Primary care, secondary care and other appropriate service providers must communicate to the patient the importance of attending appointments for diagnostic investigation and the benefits associated with early diagnosis.  Language used in verbal and written communication should be clear, accessible and reassuring. Patients should understand why they are being referred, what tests they may undergo, and what they are likely to experience.  Patients should be reassured that most people referred for further investigation do not have cancer.  Patients should also be signposted to other sources of information, any help/support they can access, how long it will take to receive their results, the method of communicating the outcome of their diagnostic tests and who to contact regarding any issues they face concerning their appointment. | [Link to section 1.14 (Patient information and support) of NICE’s guideline on suspected cancer NG12.](https://www.nice.org.uk/guidance/NG12/chapter/Recommendations-on-patient-support-safety-netting-and-the-diagnostic-process#patient-information-and-support) |
| 3 | NHS England Cancer Programme (NCD) | **Information and support**  Key area for quality improvement 3  Existing – Cross-cutting  Provision of understandable information about referral for diagnosis, encouraging attendance | We suggest retaining quality statement four in the existing quality standard, but with amendments.  In particular, we suggest that this should be updated to better reflect the need to make sure that patients and their family/carer fully understand their referral and have a better experience of care. This means not relying on a single means of communication – for example just written communication – instead providing a range of information that work for different audiences. This is because written information is not always appropriate for people with certain groups, for example those with disabilities.  Evidence from the National Cancer Patient Experience Survey (2021) indicates that only 64.1% of those surveyed felt that their referral for diagnosis was only explained in a way that they could completely understand. This figure is lower for people who are not likely to respond to written information as intended, with 51.6% of people with learning disabilities understanding their referral and 55.8% for people with blindness or sight loss.  NHS England's Digital Service Manual provides advice on making content inclusive and accessible, including requiring that considerations are made with regards to people who may have difficulty getting the healthcare they need (including those who do not have English as a first language), as well as those who struggle to read and understand words and numbers. | Please see data from the national report of the National Cancer Patient Experience Survey (2021), which shows significant amounts of people do not understand the referral information that they have been given.  <https://www.ncpes.co.uk/wp-content/uploads/2022/07/CPES21_Standard-National-Report_JK-PF-NG_RM_BA_SH_280622_FINAL.pdf>  Please see the NHS standard for creating health content, flagging the need for health information to be accessible to various audiences:  <https://service-manual.nhs.uk/content/standard-for-creating-health-content> |
| 4 | NHS Learning Disability & Autism Programme | **Information and support**  Key area for quality improvement 2  We strongly recommend a Quality Standard on improving the experience of suspected cancer care and support for people with a learning disability and autistic people. This may include:   * Adaptations to communications, interactions, environments and appointments to suit the needs of people with a learning disability and autistic people. This may involve providing accessible information, set appointment times, quiet rooms etc. Reasonable adjustments such as these must be personalised and documented. Training for staff on how to make reasonable adjustments, which are mandated under the equalities act.   We strongly recommend a Quality Standard that ensures that reasonable adjustments are proactively applied to all stages of the clinical pathway for suspected cancer, including ensuring that:   * all campaigns and public facing information about cancer is available in easy read, plain English and video formats. * additional supports and desensitisation approaches are available to ensure attendance and engagement with diagnostic tests, particularly where anxiety and distress are heightened. * clinicians follow up any non-attendance at assessment or treatment appointments, as this may reflect a lack of capacity to understand their importance and non-attendance may therefore constitute a safeguarding concern. * screening is undertaken proactively and at a younger age (e.g. for bowel cancer) than the general population to reduce the risks presented by late recognition. * the mental capacity act and best interest processes are followed for patients who lack capacity, to ensure that informed decisions are made about how to maximise engagement with assessment and treatment * clinicians are aware of supports available through acute learning disability liaison nurses and community learning disability teams * clinicians are reminded of the importance of avoiding unconscious bias and utilising DNACPRs appropriately * Staff completion of the Oliver McGowan mandatory training, which aims to provide the health and care workforce with the right skills and knowledge to provide safe, compassionate and informed care to autistic people and people with a learning disability. * The completion of learning disability annual health checks and health action plans as part of assessment and follow up, knowing that annual health checks are a successful mechanism for detecting unmet need. * Asking for feedback from patients around attitude and behaviour of health staff and their experience of care. * Clarity around capacity and consent- particularly in relation to cervical screening where we know some people with a learning disability are being exempted by family and GP without a capacity assessment so cervical cancer is a risk of going undetected. * Ensuring primary care share information on reasonable adjustments with secondary care through referral forms and subsequent onward referrals * Many people with a learning disability, autism or both may be more anxious than others about change of routine or regularity. The idea that they cannot maintain their daily routines because something new has arisen that means they have to take new steps, like making an appointment to see their doctor and with implications that could potentially upset their routines considerably further may be something they find difficult. They may respond to this with denial. So health education about the need to respond to symptoms like breast lumps, blood in spit, urine or poo, or moles that are growing or ulcerating etc may need to be enhanced and refocussed for these patients. * Doctors may need to be advised that for some autistic people the news that an initial test has produced a worrying result and that further investigation is needed may be very difficult to hear because worrying. | Studies ([Alborz et al, 2005](https://doi.org/10.1258%2F1355819054338997)) have shown that people with a learning disability and autistic people can face barriers to accessing certain healthcare facilities and so a Quality Standard that addresses barriers will improve their health outcomes.  People with a learning disability and autistic people can benefit from:   * being able to access information in easy read or other accessible formats.   healthcare professionals taking time to ensure that they understand what is happening and the choices that they can make.  This may help to narrow the gap for people with a learning disability and autistic people in terms of national metrics i.e.   * How many people with a learning disability or autistic people are diagnosed at stage 1 or 2 (the national LTP target is 75% by 2028) (a quality standard could be that ICBs or cancer networks report the percentage)   - What is the 5 year survival rate for people with a learning disability or autistic people?  - What percentage of diagnoses (or point of reassurance) are made within 28 days for autistic people?  - What proportion of tests are carried out at CDCs for autistic people? | It is a [legal duty](https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty#what-we-mean-by-reasonable-adjustments) to make adjustments for people with a learning disability and autistic people.  Public Health England has produced a [suite of easy read guides](https://www.gov.uk/government/collections/nhs-population-screening-access-for-all#easy-read-resources) to help explain screening tests to people with a learning disability and autistic people.  All organisations that provide NHS care are legally required to follow the [Accessible Information Standard.](https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/)  Suspected cancers may be identified later amongst people with a learning disability, autism or both due to:   * screening inequalities resulting in a lower uptake of screening in these populations * difficulties understanding and retaining information about the signs and symptoms of cancer to look out for * difficulties accessing healthcare following recognition of signs and symptoms due to anxiety, cognitive impairments and health inequalities   There is [evidence](https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf) that some cancers (e.g., bowel cancer) may cause death at a younger age amongst people with a learning disability than the general population.  Many autistic people may be more anxious than others at with a change of routine or regularity. The idea that they cannot maintain their daily routines because something new has arisen that means they have to take new steps, like making an appointment to see their doctor and with implications that could potentially upset their routines considerably further may be something they find difficult. They may respond to this with denial. So health education about the need to respond to symptoms like breast lumps, blood in spit, urine or poo, or moles that are growing or ulcerating etc may need to be enhanced and refocussed for them. page 30 [leder-main-report-hyperlinked.pdf (kcl.ac.uk)](https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf)  Doctors may need to be advised that for some autistic people the news that an initial test has produced a worrying result and that further investigation is needed may be very difficult to hear because worrying. Being aware of how to read people’s reactions would be important. |
| 5 | SCM1 | **Information and support**  Clarity – of information, of process, etc. is essential to patients | Anxiety is a key factor during the diagnosis process. Patients need clear consistent information, they need to understand not only what is happening in this moment but also what is going to/likely to happen as they undergo tests, etc. to help reduce this anxiety, make them better informed and more able to make decisions when the time comes. Information needs to be provided in a way that they and those around them can understand and process. They need general information but they also need more specific information. They need to know definitive information to their particular type of test/suspected cancer and they need support throughout the process. Much of this will happen in General Practice where safety netting is so important  Patients also need to know where to go to for information, who can signpost, what are trusted sources, etc. | Jones, D., et al., Safety netting for primary care: evidence from a literature review. British Journal of General Practice, 2019. 69(678): p. e70-e79.  Swann R, Lyratzopoulos G, Rubin G, Pickworth E, McPhail S. The frequency, nature and impact of GP-assessed avoidable delays in a population-based cohort of cancer patients. Cancer epidemiology. 2020;64:101617.  Nicholson BD, Mant D, Bankhead C. Can safety-netting improve cancer detection in patients with vague symptoms?. BMJ. 2016;355:i5515. Published 2016 Nov 9. doi:10.1136/bmj.i5515  Recommendation in NICE Guideline (NG12) Suspected cancer: recognition and referral |
| 6 | SCM1 | **Information and support**  Consistency | This may be more difficult for the QS to achieve but is important to patients nonetheless. Patients need some stability at this difficult time. They need some consistency in terms of the treatment they need/receive, the information they receive and they need to know that they will receive this – different treatment timescales in different treatment centres is not helpful to patients. They also need to know that they are not disadvantaged in terms of consistency of treatment because of who they are, where they live, etc. | No information submitted |
| 7 | SCM1 | **Information and support**  Timeliness – in terms of waiting for appointments, waiting for tests and waiting for results and next steps | Anxiety waiting for tests and results – even the ‘two week wait’ period is a long time. Things don’t always move as quickly after the initial appointment – no news is not always good news. Days can feel like weeks so patients need information quickly (but not at the expense of being definitive). The issue of one test over several successive tests is also important to patients. Getting the first appointment is key but then waiting for tests or follow up appointments can take more time than a patient would like/expect. | Two Week Wait (2WW) to be replaced with the Faster Diagnosis Standard – see NHS publication ‘Clinically-led review of NHS cancer standards Models of care and measurement’– March 2022 which will be of benefit to patients. This needs to be embedded and kept under review.  <https://www.england.nhs.uk/wp-content/uploads/2022/03/B1320-clinically-led-review-of-nhs-cancer-standards-models-of-care-and-measurement_090322.pdf>  <https://www.england.nhs.uk/cancer/faster-diagnosis/> |
| 8 | SCM2 | **Information and support**  Patient information  Patients being investigated for suspected cancer are given clear information and support. | These pathways will be novel to most patients and induce anxiety in many. | [Recommendations on patient support, safety netting and the diagnostic process](https://www.nice.org.uk/guidance/ng12/chapter/Recommendations-on-patient-support-safety-netting-and-the-diagnostic-process)  <https://www.nice.org.uk/guidance/cg138>  Patient experience in adult NHS services: improving the experience of care for people using adult NHS services Clinical guideline [CG138]  Published: 24 February 2012 Last updated: 17 June 2021 |
| 9 | SCM3 | **Information and support**  Provision of written information to explain to people that they are on a suspected cancer pathway | People referred on the suspected cancer pathway should be given written information to provide explanation and reduce delays in attendance of appointments and investigations. | Some good examples of written information on some Trust’s websites, but nothing standardised in various formats  [Cancer Keys What to tell a patient at the point of a suspected cancer referral](https://www.gatewayc.org.uk/cancer-keys/what-to-tell-a-patient-at-the-point-of-a-suspected-cancer-referral/) |
| 10 | SCM4 | **Information and support**  Key area for quality improvement 1  QS 4. Encouraging attendance at Cancer Services states “People with suspected cancer who are referred to a cancer service are given written information encouraging them to attend”. Suggestion should this read “information in a format the person can understand therefore taking consideration of the whole population e.g. people who may be blind, low literacy rate, learning difficulty etc – may require reasonable adjustments in line with Equality Act. (Appreciate the guidance 1.114.6 and 1.114.7 does state re: the different formats available but the Quality standard is specific re; written format and consideration should be made to change this). | Lower health literacy was associated with greater difficulties understanding and processing cancer related information, poorer quality of life and poorer experience of care.  In the evidence descendants with intellectual disabilities, symptoms suggestive of cancer had tended to be identified most frequently as an emergency and at a late stage. There is a need for greater awareness of symptoms of cancer in this population, a lower threshold for referral by General Practitioners (GPs), accelerated access to diagnosis and treatment and consideration paid to lowering the age for colorectal screening. | [The role of health literacy in cancer care: A mixed studies systematic review The role of health literacy in cancer care: A mixed studies systematic review - PubMed (nih.gov)](https://pubmed.ncbi.nlm.nih.gov/34767562/)  Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. [Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources | BMJ Open](https://bmjopen.bmj.com/content/12/3/e056974) |
| 11 | SCM4 | **Information and support**  Key area for quality improvement 2  QS 4. Encouraging attendance at Cancer Services.    Consideration to be made re: a follow up mechanism for non-attendance which could then improve outcomes for people with cancer as some of the research suggests this could be administrative errors. | Evidence suggests several potential explanations for non-attendance at urgent referral appointments for suspected cancer e.g. communication, appointment systems particularly for older patients and those from more derived areas, patients leading “difficult lives” and expectations of patients.  We know that if a cancer is detected early the outcome for the individual is greatly improved. | Non-attendance at urgent referral appointments for suspected cancer: a qualitative study to gain understanding from patients and GPs. [Non-attendance at urgent referral appointments for suspected cancer: a qualitative study to gain understanding from patients and GPs - PubMed (nih.gov)](https://pubmed.ncbi.nlm.nih.gov/31740457/) |
| 12 | Target Ovarian Cancer | **Information and support**  Encouraging attendance at cancer services | The existing QS4 should be updated to include provision of written information.  specifically on support services/advice lines for different cancers provided by the voluntary sector.  Target Ovarian Cancer has found that those users of our services often do not find or engage with us until after their diagnosis so early engagement at pre-diagnosis could help encourage attendance at cancer services. | No information submitted. |
| 13 | MDS UK Patient Support Group | **Recognition of symptoms: awareness and response to symptoms**  Key area for quality improvement 2 Improve knowledge of GPs with regards to MDS. Specifically – include the fact that repeat abnormal blood results need to be referred to a haematologist for further investigation, as per BSH Clinical Guidelines. | We receive numbers of calls from patients who report many months, or even many years of having abnormal blood results, but not being investigated sufficiently, nor being sent to a haematologist.  Of all patients with anaemia, 30% to 40% (depending on publications) of them have an ‘unexplained’ anaemia – which will include MDS patients. These need to be assessed properly, to offer best care. | <http://www.ukmdsforum.org.uk/education-and-trainees-corner/gp-factsheet>  [British Society for Haematology guidelines for the diagnosis and evaluation of prognosis of Adult Myelodysplastic Syndromes](https://onlinelibrary.wiley.com/doi/10.1111/bjh.17621)  [Unexplained Anemia in the Elderly](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8714032/) |
| 14 | MDS UK Patient Support Group | **Recognition of symptoms: awareness and response to symptoms**  Key area for quality improvement 1  Include the condition MDS Myelodysplastic Syndromes in the list of haematological cancers which need to be on the radar of GPs and general haematologists. Whilst Low-Risk MDS may not be viewed as a form of typical blood cancer, High-risk MDS is clearly acknowledged to be a blood cancer. | MDS patients are clearly at disadvantage of being properly treated with the precise care they require for this complex disease. As a support group we receive many calls from patients who report that their GP is barely aware of the potential dangers of MDS, and the issues of Quality of Life. There are an increased number of supportive care and clinical trials open to low-risk and high-risk MDS, which patients should have access too. | <http://www.ukmdsforum.org.uk/education-and-trainees-corner/gp-factsheet>  <https://patient.info/doctor/myelodysplastic-syndromes-pro> |
| 15 | NHS England Cancer Programme (NCD) | **Recognition of symptoms: awareness and response to symptoms**  Quality improvement area 2  New – Cross-cutting  Access to decision support tools to aid in referral of suspected cancer | Clinical decision support (CDS) tools are designed to support GPs in clinical decision making, such as whether to refer or request further diagnostic investigation in patients where they believe there is a risk of cancer. These tools do not replace clinical judgement but inform patient management decisions.  CDS tools can be broadly categorised into:  Algorithm-based tools, which calculate the risk of a patient having a undiagnosed cancer   * Symptom reference guides, which can be visual summaries of interactive illustrations of NG12 recommendations. * Requested advice, where GPs can seek advice from consultants through the NHS Electronic Referral System.   The NHS Cancer Programme set out in its 2022/23 Cancer Alliance Planning Support Pack that Cancer Alliances should ensure that CDS tools should be available for use in 100% of GP practices by March 2023. £10 million funding was rolled into place-based funding allocations to support this.  Investing in and using these tools help support GPs make the most appropriate decisions for cancer referrals. This has two key benefits: making sure that patients who are likely to have cancer receive a diagnosis, as well as reducing the number of inappropriate referrals and therefore freeing up diagnostic capacity and funds for those more likely to have cancer. | Please see an overview of information by Cancer Research UK on clinical decision support tools.  <https://www.cancerresearchuk.org/health-professional/diagnosis/suspected-cancer-referral-best-practice/clinical-decision-support-tools-overview#CDS_Overview0>  The NHS Cancer Programme also provided a support pack to Cancer Alliances on implementing CDS tools in GP practices. This document has not been published but is available on request. |
| 16 | NHS Learning Disability & Autism Programme | **Recognition of symptoms: awareness and response to symptoms**  Key area for quality improvement 3  Add to existing Quality standards for suspected cancers: to include reasonable adjustments for people with a disability.  Statement 1 GPs have direct access to diagnostic endoscopy, ultrasound, MRI, X-ray and CT for people with suspected cancer.  Statement 2 People presenting in primary care with symptoms that suggest oesophageal or stomach cancer have an urgent direct access upper gastrointestinal endoscopy.  Statement 3 Adults presenting in primary care with symptoms that suggest colorectal cancer, who do not meet the referral pathway criteria, have a test for blood in their faeces.  Statement 4 People with suspected cancer who are referred to a cancer service are given written information encouraging them to attend.  Include an additional statement re the availability of resources for primary care clinicians to support them to make reasonable adjustments for groups that need them. | Reasonable adjustments (as mandated by the equalities act) are essential so that people with a learning disability and autistic people can access cancer services fairly. | See Key area 1 re health inequalities experienced by people with a learning disability and autistic people.   * Not aware of literature specific to autistic people’s feelings in relation to cancer but a recent paper published has found high levels of health anxiety in autistic adults (unfortunately they did not collect information about current health status, so it is impossible to fully interpret if the health of the autistic and non-autistic samples is comparable – and therefore to interpret whether the anxiety about one’s health is pathological or well founded): [Health anxiety in autistic adults – ScienceDirect](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.sciencedirect.com%2Fscience%2Farticle%2Fpii%2FS1750946723000466&data=05%7C01%7Cwendy.hicks1%40nhs.net%7Ce259c89669724ad30efd08db41be8d92%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638176058887606905%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=rUNqnxqTfhyOTESGQF%2BBNs06jXN9GHwhgws2miAhISY%3D&reserved=0) * Also of relevance, there is an increasingly widespread idea that autistic people have higher pain threshold relative to non-autistic people but actually when this is experimentally tested, the opposite is true, i.e., autistic people are more sensitive to pain – but the perceived difference might instead be a function of being less likely to communicate their pain - [Indifference or hypersensitivity? Solving the riddle of the... : PAIN (lww.com).](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fjournals.lww.com%2Fpain%2FAbstract%2F2023%2F04000%2FIndifference_or_hypersensitivity__Solving_the.14.aspx&data=05%7C01%7Cwendy.hicks1%40nhs.net%7Ce259c89669724ad30efd08db41be8d92%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638176058887606905%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=mC4LQIySusY7jfnsmyGdQiCuKnXYFSN4Mz9yfDr8vUU%3D&reserved=0) * people with a learning disability, people with autism or both may have difficulties identifying and communicating about physical pain and emotional distress, which can result in diagnostic overshadowing and delayed diagnosis. * Some other related considerations is that for about half of autistic people, but not all, alexithymia, that is, difficulty identifying internal emotional states, is a challenge. This means some autistic people can struggle to process, recognise, identify, or understand their own emotions, all of which can lead to different reactions to emotive situations (including hearing about a potential suspect test result) than medical professionals might expect – letting people know of this would no doubt be helpful - [Investigating alexithymia in autism: A systematic review and meta-analysis - PMC (nih.gov)](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.ncbi.nlm.nih.gov%2Fpmc%2Farticles%2FPMC6331035%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7Ce259c89669724ad30efd08db41be8d92%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638176058887606905%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=HOBzfX91fnPpoVRjaQUH7aqwAlGIE%2BtpFo0XbT17Q7o%3D&reserved=0) * Similarly, autistic people have difficulties with interoception (correctly recognising and identifying internal bodily signals which can include pain, discomfort, changes in heart rate, temperature and so on): [Discrepancies between dimensions of interoception in autism: Implications for emotion and anxiety – ScienceDirect.](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.sciencedirect.com%2Fscience%2Farticle%2Fabs%2Fpii%2FS0301051115300958&data=05%7C01%7Cwendy.hicks1%40nhs.net%7Ce259c89669724ad30efd08db41be8d92%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638176058887606905%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=ktc41q8HjvQNeQdk6Wp35spowUqXLIhpyQdfSQWGb5k%3D&reserved=0) * Autistic people are also found to have higher levels of a construct which is a component part of anxiety, referred to specifically as intolerance of uncertainty, which means the uncertainty associated with waiting for test results, while anxiety inducing for everyone, could be much more anxiety inducing for autistic people: [The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis - PubMed (nih.gov)](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fpubmed.ncbi.nlm.nih.gov%2F32564625%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7Ce259c89669724ad30efd08db41be8d92%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638176058887606905%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=voXLUuQZYOYqC2Wq7HCAOGecnUc%2FBxjvlRN00fTn2K0%3D&reserved=0) |
| 17 | NHSE Learning Disability & Autism Programme | **Recognition of symptoms: awareness and response to symptoms**  Key area for quality improvement 1  We strongly recommend that health education around suspected cancer is enhanced and focussed for people with a learning disability and autistic people. | This would improve awareness of the need to respond to symptoms which may be different for people with a learning disability or overshadowed | The Kings College London 2021 [LeDeR report](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.kcl.ac.uk%2Fioppn%2Fassets%2Ffans-dept%2Fleder-main-report-hyperlinked.pdf&data=05%7C01%7Cwendy.hicks1%40nhs.net%7Cc7a424d1ec5b4d8a169108db4174880c%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638175740967641233%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=O4bUH0MQt5LjjMR%2BoKd9FYD3EV1vnJoASOIa%2FcRzLb0%3D&reserved=0) shows that, generally, people with a learning disability receive a poorer standard of care, and die earlier, than people without a learning disability  The report also says that cancer was the 4th biggest killer for people with a learning disability in 2021 with 11.4% of people with a learning disability dying from cancer in 2021. Of these, the leading cancers were of the digestive organs (24.7%) (with 13.6% being of the colon and rectum). The second most common cancers were Lymphoid, haematopoietic and related tissue (11.3%), followed by cancer of the respiratory and intrathoracic organs. (8.4%) 7.7% being of the lung and bronchus)  It highlights that, of the people with a learning disability who had a LeDeR review in 2021, for people who died who had cancer as a Long Term Condition, 8% of those deaths were avoidable. They were more than twice as likely (x 2.04) to die an avoidable death than someone who did not have cancer in the LeDeR group.  There is evidence that:  [people with a learning disability receive a poorer standard of care, and die earlier](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.england.nhs.uk%2Fpublication%2Fleder-action-from-learning%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7C5112f802c6ab41902d9108db40b7f23f%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638174931297435468%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Hmk%2F4%2FdbUN8RrhZmWfT9YQgt0o7O1VrNY4JTxi4Z2JE%3D&reserved=0), than people without learning disabilities  Whilst not the focus of this review it may be worth saying that. [Screening inequalities](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fphescreening.blog.gov.uk%2F2017%2F09%2F12%2Fscreening-inequalities-and-what-were-doing-about-them%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7C5112f802c6ab41902d9108db40b7f23f%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638174931297435468%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=DCBHEdCaCv2zpekA4BmEJbbwqTtGjaMkzeAzlP%2BEJE4%3D&reserved=0) exist among people with a [learning disability](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nhs.uk%2Fconditions%2Flearning-disabilities%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7C5112f802c6ab41902d9108db40b7f23f%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638174931297435468%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=F%2FsUuHiMYWm9PE5KaRHzfnhk9Qu9gLsMWO5pO0%2FpFnM%3D&reserved=0), autism or both and they are less likely to access screening:   * [breast screening uptake is lower in women with a learning disability](https://gbr01.safelinks.protection.outlook.com/?url=http%3A%2F%2Fwebarchive.nationalarchives.gov.uk%2F20180328130852tf_%2Fhttp%3A%2Fcontent.digital.nhs.uk%2Fcatalogue%2FPUB22607%2FHealth-care-learning-disabilities-2014-15-summary.pdf%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7C5112f802c6ab41902d9108db40b7f23f%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638174931297435468%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=qy7deYRDEPKhMpI5B9cq2J%2FPARqkXs6%2FMLrTbNu8t9g%3D&reserved=0) compared to the general population * [engagement in bowel cancer screening can be difficult for people with a learning disability](https://gbr01.safelinks.protection.outlook.com/?url=http%3A%2F%2Fwww.bristol.ac.uk%2Fmedia-library%2Fsites%2Fcipold%2Fmigrated%2Fdocuments%2Ffullfinalreport.pdf&data=05%7C01%7Cwendy.hicks1%40nhs.net%7C5112f802c6ab41902d9108db40b7f23f%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638174931297435468%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=vg54PTq%2FyCUt%2Bdmoqg4iocy7S8sG8M6U0MsWCba%2FDVI%3D&reserved=0) * [cervical screening uptake is lower in people with a learning disability](https://gbr01.safelinks.protection.outlook.com/?url=http%3A%2F%2Fwebarchive.nationalarchives.gov.uk%2F20180328130852tf_%2Fhttp%3A%2Fcontent.digital.nhs.uk%2Fcatalogue%2FPUB22607%2FHealth-care-learning-disabilities-2014-15-summary.pdf%2F&data=05%7C01%7Cwendy.hicks1%40nhs.net%7C5112f802c6ab41902d9108db40b7f23f%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638174931297435468%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=qy7deYRDEPKhMpI5B9cq2J%2FPARqkXs6%2FMLrTbNu8t9g%3D&reserved=0) compared to everyone else   In a study published in BMJOpen in 2021 evidence showed that more than a third [of people with an intellectual disability] (35%; n=162) had cancer diagnosed via emergency presentations. Almost half (45%; n=228) of cancers were at stage IV when diagnosed. More than a third (36%; n=309) of underlying causes of deaths were of cancers of the digestive system; almost half of these (48%; n=147) were cancer of the colon, rectum or anus. Of those who died with colorectal cancer, 43% were below the age threshold for colorectal screening |
| 18 | Young Lives Versus Cancer | **Recognition of symptoms: awareness and response to symptoms**  Recognition of and investigation for suspected cancer in children and young people | Significant improvement is still required to ensure that children and young people with cancer receive the right diagnosis and referral as soon as possible after presenting to the health service with symptoms.  It is critically important that the signs and symptoms of cancer in children and young people are spotted as early as possible so they are diagnosed quickly, referred as soon as possible, and therefore access treatment as soon as possible and avoid diagnosis in an emergency presentation.  Enhanced support and training for GPs and other front-line medical and healthcare professionals to identify cancers in children and young people is essential, as equipping professionals to recognise cancer signs and symptoms in children and young people is key to improving patient outcomes and experiences through earlier and faster diagnosis. | The “[Best Chance from the Start](https://www.younglivesvscancer.org.uk/wp-content/uploads/2018/08/The-Best-Chance-from-the-Start-Report.pdf#:~:text=The%20best%20chance%20from%20the%20start%20explores%20the,be%20better%20supported%20in%20the%20UK%20health%20system.)” research by Young Lives vs Cancer has shown that over half of young people (52%) and almost half of parents of children with cancer (49%) visit their GP at least three times before their cancer is diagnosed, with a quarter of young people (24%) and one in five parents (18%) requiring five visits before receiving a diagnosis.  These trends continue to be echoed in the results of the latest (2021) [Under-16 Cancer Patient Experience Survey](https://www.under16cancerexperiencesurvey.co.uk/), where more than a third of respondents (37%) said they visited their GP more than once, with almost a quarter (24%) visiting their GP three or more times, before they were told they needed to go to hospital because of their cancer or tumour.  Young Lives vs Cancer research also found that GPs and other health care professionals often find it difficult to identify suspected cancer in children and young people; one third of GPs reported that insufficient opportunities to gain experience in the care of children and young people during their initial training was one of the top barriers to identifying cancer in children and young people, and more than half (53%) said continuing professional development schemes on cancer in children and young people would be beneficial in providing them with additional support or advice on diagnosis.  [Cancer Research UK](https://www.cancerresearchuk.org/health-professional/young-peoples-cancers-diagnosis-statistics#heading-Zero) outline that emergency presentation is the most common route of diagnosis for cancer in young people. |
| 19 | NHS England Cancer Programme (NCD) | **Recognition of symptoms: non-specific symptoms**  Key area for quality improvement 1  New – Cross-cutting  Non-specific symptom pathways for patients who do not fit clearly into a single referral pathway | Patients who do not fit clearly into a single ‘urgent cancer’ referral pathway, as defined by NG12, but who are nonetheless at risk of being diagnosed with cancer (for example those with unexplained weight loss, abdominal pain or nausea, and/or a GP 'gut feeling' about cancer) are referred to new non-specific symptom (NSS) pathways.  The new quality standard should be updated to reflect the development of pathways for patients with NSS that can indicate cancer. These pathways have been developed to capture a cohort of patients who often saw their GP multiple times before referral, presented in an emergency setting, presented with late stage pathways, or referred onto multiple urgent pathways with resulting inefficiencies in healthcare provision.  As of February 2023, 104 NSS pathways have been established, including pathways for lung, pancreatic, head and neck, upper and lower GI cancers. Over 78,000 patients have been seen, with the 19% meeting all pathway milestones. For Cancer Alliances with 100% population coverage for these services, we estimate that patients with core NSS symptoms account for approximately 2-5% of total urgent cancer referrals.  An evaluation by IPSOS of the Faster Diagnosis Programme in May 2022 indicated that NSS pathways performed better than non-NSS pathways from November 2021 onwards.  Cancer Alliances were asked in 2022/23 by the NHS Cancer Programme to complete the rollout of NSS pathways to achieve 100% population coverage by March 2024. | Please see the NHS Cancer Programme’s strategic approach to delivering faster diagnosis of cancer, which includes more information about NSS pathways:  <https://www.england.nhs.uk/wp-content/uploads/2019/07/B1332-NHS-Cancer-Programme-Faster-Diagnosis-Framework-v5.pdf>  Commissioned internal evaluations may be available to NICE if requested. |
| 20 | Pancreatic Cancer UK | **Recognition of symptoms: non-specific symptoms**  GPs should refer anyone aged 55 or over with weight loss and upper abdominal pain, vomiting, nausea, reflux or dyspepsia for an OGD and CT of pancreas. | There is a lot of overlap between Upper GI symptoms and we have limited data on how GPs utilise different referral pathways for this cohort of patients.  Therefore, there is need for further data about the referrals patterns and outcomes for people presenting with symptoms that, as defined by the NG12 referral criteria, could be referred for suspected pancreatic cancer or oesophageal or stomach. | Information from a forthcoming publication was submitted to support this suggestion. |
| 21 | SCM1 | **Recognition of symptoms: non-specific symptoms**  Access to tests/treatment, quickly and effectively, irrespective of who you are, where you live, the type of cancer, etc. patients want to know and understand the options available at every point in the process. It is important, therefore, that when considering access there is a Quality Standard that is applicable to all cancers, particularly those are not obvious or site specific | The current standard focuses on certain cancer types which is not of most benefit to patients who are not suspected to have these types of cancer.  The standard will need to consider a range of access issues and those with non-specific symptoms is | There is much anecdotal evidence in relation to this area but work has been carried out to understand the impact of faster referral for those with non-specific symptoms. As an example, please see the following which considered mortality- Chapman, D., Poirier, V., Vulkan, D. *et al.* First results from five multidisciplinary diagnostic centre (MDC) projects for non-specific but concerning symptoms, possibly indicative of cancer. Br J Cancer 123, 722–729 (2020). <https://doi.org/10.1038/s41416-020-0947-y> |
| 22 | SCM5 | **Recognition of symptoms: non-specific symptoms**  NSS | * Suggested minimum referral criteria for NSS services and recommendations for filter tests? * And recommendations for essential pre-referral tests across all 2WW pathways? | No information submitted |
| 23 | Bowel Cancer UK | **Diagnostic tests: GP direct access to tests and scans**  Direct access to diagnostic tests | GPs have direct access to diagnostic endoscopy, ultrasound, MRI, X-ray and CT for people with suspected cancer.The current standard’s rationale is still valid: People who visit their GP with symptoms that may suggest cancer are sent for diagnostic tests to confirm or refute a cancer diagnosis. Enabling GPs to use direct access for specific tests is cost effective and will reduce the time to reach a diagnosis.  NHS England has recently (Nov 2022) announced an expansion of direct access to diagnostic scans from primary care. The standard should remain as this practice is fully embedded and equitable utilisation of this scheme is achieved to the benefit of patients across the country. | [NHS gives GP teams direct access to tests to speed up cancer diagnosis (News item, 16 November 2022)](https://www.england.nhs.uk/2022/11/nhs-gives-gp-teams-direct-access-to-tests-to-speed-up-cancer-diagnosis/) |
| 24 | NHS England Cancer Programme (NCD) | **Diagnostic tests: GP direct access to tests and scans**  Key area for quality improvement 4  Existing – Cross-cutting  GP direct access to diagnostic tests for people with suspected cancer | We believe that quality statement one in the existing quality standard should be retained, particularly given commitments by NHS England and the UK Government to expand and accelerate direct access for GPs to diagnostic tests for suspected cancer which fall outside of NICE's guidelines threshold for an urgent suspect cancer referral. Under this scheme, around 67,000 people who are usually diagnosed with cancer through non-urgent testing will now be eligible for fast-tracking | Please see reference to a commitment by NHS England to provide direct access to diagnostic tests to speed up cancer diagnosis.  <https://www.england.nhs.uk/2022/11/nhs-gives-gp-teams-direct-access-to-tests-to-speed-up-cancer-diagnosis/> |
| 25 | NHS England Cancer Programme (NCD) | **Diagnostic tests: GP direct access to tests and scans**  General  Existing – Site-specific  Removal of quality statement two | Following conversations with clinicians, we recommend the removal of quality statement two currently outlined in the existing quality standard. The rationale for this is that quality statement one provides already covers diagnostic endoscopy, which makes quality statement two duplicative. We do not think the scope for quality improvement in this area warrants a separate quality statement. | No information submitted |
| 26 | NHS England Cancer Programme (NCD) | **Diagnostic tests: GP direct access to tests and scans**  Key area for quality improvement 5  New – Site-specific  Straight-to-test with clinically led triage models for prostate and colorectal pathways | Straight-to-test with clinically-led triage models (particularly for prostate and colorectal cancer pathways) are in place to streamline the start of the pathway. These enhance the interface with primary care, maximising use of diagnostics and support the implementation of best practice timed pathways.  Best practice timed pathways (BPTP) have been developed for prostate and colorectal cancer, to support efforts to shorten diagnosis pathways, reduce variation, improve experience of care and meet the Faster Diagnosis Standard (FDS).  Straight-to-test with clinically-led triage models play an important role in streamlining the beginning of the pathway. According to NICE Prostate Cancer Guidelines (NG131), this can be done by a suitably experienced urologist physician or cancer CNS. If deemed medically fit, the appropriate first line investigations should be performed and reported within three days of triage so that this cohort can progress on the pathway in the same timeframes.  Introducing BPTP with these elements can reduce demand in outpatient clinics, target resources at patients with cancer by removing non-cancer patients earlier in the pathway, as well as improve quality, safety and effectiveness of care, while reducing variation and improving outcomes. | Please see guidance by the NHS Cancer Programme for local health and care systems on implementing timed cancer diagnostic pathways for:  [Prostate cancer](https://www.england.nhs.uk/wp-content/uploads/2018/04/B1348_Prostate-cancer-timed-diagnostic-pathway.pdf)  [Colorectal cancer](https://www.england.nhs.uk/wp-content/uploads/2018/04/B2119-implementing-timed-colorectal-cancer-diagnostic-pathway.pdf)  [Please see the NHS Cancer Programme’s strategic approach to delivering faster diagnosis of cancer](https://www.england.nhs.uk/wp-content/uploads/2019/07/B1332-NHS-Cancer-Programme-Faster-Diagnosis-Framework-v5.pdf), which includes more information about best practice timed pathways:  <https://www.england.nhs.uk/wp-content/uploads/2019/07/B1332-NHS-Cancer-Programme-Faster-Diagnosis-Framework-v5.pdf> |
| 27 | Pancreatic Cancer UK | **Diagnostic tests: GP direct access to tests and scans**  Urgent direct access to CT scans for people with suspected pancreatic cancer | Urgent access to a CT scan upon first presentation of symptoms is critical to ensure earlier and faster diagnosis of pancreatic cancer. Currently 80% of pancreatic cancer cases are diagnosed late and people experience long delays between first presentation to primary care and referral. Faster detection and diagnosis is vital for pancreatic cancer, as there is rapid deterioration in physical, nutritional and psychological condition such that people are often unable to tolerate treatment and have poor quality of life.  Despite NHS England expanding direct access to diagnostic scans across all GP practices, it is currently unclear to what extent GPs have direct access to CT scans and if this is a common route of referral for suspected pancreatic cancer.  In addition, pancreatic cancer symptoms are vague and non-specific and we have limited data on which pancreatic cancer symptoms lead GPs to use direct access pathways, non-specific symptom pathways (NSS) or existing site specific cancer referral pathways. Therefore, there is a need to develop the evidence base about which pancreatic cancer symptoms lead to a referral and what referral pathways are being used.  If we want to see improvements in stage of diagnosis for people with pancreatic cancer as well as early access to supportive care and vital treatment which is vital given the fast pace of disease progression, we need to ensure that direct CT access is an option for everyone with PC regardless where they live and including this as quality statement is key to implementation. | Information from a forthcoming publication was submitted.    NICE Guideline 12  1. 2.5. Consider an urgent direct access CT scan (to be done within 2 weeks), or an urgent ultrasound scan if CT is not available, to assess for pancreatic cancer in people aged 60 and over with weight loss and any of the following: diarrhoea, back pain, abdominal pain, nausea, vomiting, constipation or new‑onset diabetes. [2015] |
| 28 | Pancreatic Cancer UK | **Diagnostic tests: GP direct access to tests and scans**  Direct follow up in secondary care for those with suspicious / abnormal finding through GP direct access, without the need of an urgent GP referral. | GP direct access can incur delays if the test result goes back to the GP and then requires an urgent referral from their GP before follow up in secondary care. The best practice in this scenario is for the patient to be followed up directly by a secondary care professional.  There is variation across the UK in GP direct access and the follow up pathways that people go on. | Information from a forthcoming publication was submitted to support this suggestion. |
| 29 | SCM2 | **Diagnostic tests: GP direct access to tests and scans**  Key area for quality improvement 1  Enhanced Primary Care Access to Diagnostic tests  Patients with suspected cancer have improved access to diagnostic tests requested from primary care, resulting in fewer A&E attendant diagnoses of cancer and ideally in time a reduction in stage at diagnosis. | Some published data below demonstrate that a minority of cancer diagnoses are being made on diagnostic tests requested directly from primary care and that too many are still being diagnosed through A&E departments.  One in ten scans performed for initial cancer investigations were referred directly from Primary care in 2017/8.  2006-2015 against an overall decrease in the percentage of patients diagnosed with cancer through an emergency presentation (from 24% in 2006 to 20% in 2015), the likelihood of emergency presentation via GP referral decreased, coupled with an increased likelihood of emergency presentation via A&E, even after accounting for sociodemographic and cancer site case mix over time. Among patients presenting as emergencies, patients living in areas of greater deprivation were less likely to be diagnosed via the GP-EP sub-route, and more likely to be diagnosed via the AE-EP sub-route. There was large heterogeneity in sub-route profile by cancer site. | NHS England (2018) [Diagnostic imaging dataset annual statistical release 2017/18](https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/11/Annual-Statistical-Release-2017-18-PDF-1.6MB-1.pdf) (accessed 13 Dec 2019).  Cancer diagnoses after emergency GP referral or A&E attendance in England: determinants and time trends in Routes to Diagnosis data, 2006–2015  Annie Herbert, Gary A Abel, Sam Winters, Sean McPhail, Lucy Elliss-Brookes and Georgios Lyratzopoulos  British Journal of General Practice 2019; 69 (687): e724-e730. DOI: <https://doi.org/10.3399/bjgp19X705473>  As set out in NG12. |
| 30 | SCM2 | **Diagnostic tests: GP direct access to tests and scans**  Equality of access  Patients should expect the same high quality service irrespective of personal characteristics or geographical location. | As these pathways become established as the route to cancer diagnosis for many we must ensure we do better at promoting and delivering equal access to narrow inequalities.  The incidence and mortality of cancer is considerably higher in deprived groups compared with more affluent groups.  Marmot 10 Years on:  Recommendations for taking action  • Develop a national strategy for action on the social determinants of health with the aim of reducing inequalities in health.  • Ensure proportionate universal allocation of resources and implementation of policies.  • Early intervention to prevent health inequalities.  • Develop the social determinants of health workforce.  • Engage the public.  • Develop whole systems monitoring and strengthen accountability for health inequalities | [Public Health England: Health Inequalities in Cancer](https://www.bing.com/ck/a?!&&p=c174ce3db7bbb46aJmltdHM9MTY4NTIzMjAwMCZpZ3VpZD0zZDRjMjRmZS0wZTgwLTZjMDItMjY0Yi0yYjZiMGY3YjZkNjgmaW5zaWQ9NTE5Nw&ptn=3&hsh=3&fclid=3d4c24fe-0e80-6c02-264b-2b6b0f7b6d68&psq=Public+Health+England%3a+Health+Inequalities+in+Cancer&u=a1aHR0cHM6Ly9maW5nZXJ0aXBzLnBoZS5vcmcudWsvZG9jdW1lbnRzL0hlYWx0aF9pbmVxdWFsaXRpZXNfY2FuY2VyLnBkZg&ntb=1)  [Health Equity in England\_The Marmot Review 10 Years On\_full report.pdf](https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on)  [Patient experience in adult NHS services Quality standard [QS15]](https://www.nice.org.uk/guidance/qs15) |
| 31 | SCM5 | **Diagnostic tests: GP direct access to tests and scans**  Direct Access Diagnostics | recommendations on direct access to urgent diagnostics to try to make these available to all G.P.s? I know NHSE are looking at this. | No information submitted |
| 32 | SCM6 | **Diagnostic tests: GP direct access to tests and scans**  Timely (performed within 2 weeks) direct access imaging (X ray, ultrasound, CT, MRI) for patients with relevant symptoms of possible cancer | NG12 recommends that GPs have direct access to a range of imaging investigations for cancer and that these tests be performed within 2 weeks of patient presentation with relevant symptoms. However, current evidence indicates that there is variation both in access to tests (particularly CT and MRI) and, where tests are available, in the time taken for these tests to be performed. Policy changes (role out of Community Diagnostic Centres and the Direct Access to Imaging Scheme) are being put in place to improve access.  The previous Suspected Cancer Quality Standard included a statement on direct access to tests but did not include a recommended time frame.  Ensuring that direct access diagnostic investigations are performed promptly (within 2 weeks), in patients presenting with relevant symptoms, could improve the quality of patient care. A Statement and Measure for this would be particularly timely given ongoing improvements in access to imaging. | - NG 12 recommends access to a range of imaging tests and that these tests be performed within 2 weeks of patient presentation in GP.  - Existing evidence (some relatively old) indicates variation in access and, where tests are available, timeliness of imaging investigations:  Access and timeliness:  [Variation in Direct Access to Tests to Investigate Cancer: A Survey of English General Practitioners](https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0159725)  Timeliness:  - [Time from presentation to pre-diagnostic chest X-ray in patients with symptomatic lung cancer: a cohort study using electronic patient records from English primary care](https://bjgp.org/content/71/705/e273)  - Systematic and scoping reviews highlighting potential benefits of GP direct access to imaging for cancer  [Impact of enhancing GP access to diagnostic imaging: A scoping review](https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0281461)  - Policy / service changes improving access  <https://www.england.nhs.uk/publication/diagnostics-recovery-and-renewal-report-of-the-independent-review-of-diagnostic-services-for-nhs-england/>  <https://www.england.nhs.uk/2022/11/nhs-gives-gp-teams-direct-access-to-tests-to-speed-up-cancer-diagnosis/> |
| 33 | SCM7 | **Diagnostic tests: GP direct access to tests and scans**  Key area for quality improvement 3  Clarifying direct access (DA) vs straight-to test (STT) diagnostic pathways for pancreatic, brain, OG and sarcoma pathways | Rationale:   * These tumour sites (left) have poorer survival rates, so a new NICE quality standard to support faster diagnosis should positively impact patient experience * According to NG12, direct access is “When a test is done and primary care retain clinical responsibility throughout, including acting on the result.” This is appropriate for non-urgent direct access NG12 tests. However, for urgent and more definitive / specialist diagnostics test (e.g. OGDs, MRIs, CTs, USS for sarcoma), NG12 makes no reference to ‘straight-to-test’ (STT) pathways. STT pathways are an improved subtype of DA pathways for urgent tests because:   + The suspected cancer clock (FDS standard) starts at the point of GP suspicion of cancer, in line with NG12 guidance for an urgent diagnostic test to take place within 2 weeks (e.g. OGD, brain MRI, CT pancreas, sarcoma tests)   + The patient still goes directly to test but those who have cancer are fast-tracked on, as they fall within the FDS standard from the outset   + Commissioners can be assured that time to diagnostic test will be no longer than 2 weeks (as stipulated by NG12 for these tumours) because the FDS clock started when the GP requested the test   + For patients found to have cancer, the STT pathway is much quicker than a DA pathway (because the test result is not passed back to the GP to do a 2WW referral). On a STT pathway, the 62-day time-to-1st treatment clock therefore starts much sooner than it does on a DA pathway   + If cancer is found, on a STT pathway, the breaking bad news consultation happens with a specialist, with CNS support (as recommended). On a DA pathway based on the current NG12 definition, this conversation would happen with a non-specialist in Primary Care, which is not ideal * There is geographical variation in how these pathways operate – some are STT whilst others are DA, as per NG12. It would be good to address this variation due to the new national drive for GP DA (which is very welcome but doesn’t work well for NG12 patients who have cancer, as described above). | Supporting Information:  It would be helpful if the new quality standard could align:   * The NICE guideline NG12 on urgent DA tests * [The BPTP for suspected OG cancer:](https://www.england.nhs.uk/wp-content/uploads/2018/04/implementing-a-timed-oesophago-gastric-cancer-pathway.pdf)  * [The forthcoming pancreatic BPTP](https://www.england.nhs.uk/cancer/faster-diagnosis/) |
| 34 | Cancer52 | **Diagnostic tests: Test results**  Improvement in waiting times for receipt of scan results and a reduction in the variation of waiting times across the country. We would like to see the metric of no more than 1% of patients waiting 6 weeks or more for their scan results being met regardless of where the patient lives and which hospital they attend. | We have evidence that some patients are waiting 6+ weeks for the results of their scans. This impacts the Faster Diagnosis Standard, which states that patients should not wait more than 28 days from referral to finding out whether they have cancer or not: <https://www.england.nhs.uk/cancer/faster-diagnosis/> | EXAMPLE: Some patients are waiting more than 6 weeks for the results of their scan. This causes additional and unnecessary stress and anxiety for the patient while they wait for their results: <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2022/03/DWTA-Report-January-2022_C4LM7K.pdf>  Waiting times for the results of scans also vary depending on the hospital and location in the country: |
| 35 | MDS UK Patient Group | **Diagnostic tests: Test results**  Key area for quality improvement 3  Improve the pathways to and from Diagnostic centres and hubs. In MDS, full results are required to properly diagnose the sub-types and risk-groups of MDS. | Survey of haematology centres reporting severe issues about results.  This yet unpublished survey was presented at the BSH 2023 by Dr Emma Das-Gupta.  The survey highlighted regional discrepancies, late results, lack of follow-up and notifications of results.  The outcome are potentially very damaging to patients, as haematologists may not be made aware of additional results, opportunities to access clinical trials, or referral to specialist centres for the more complex cases.  Related to this topic of NGS and WGS – see article by the Guardian – highlighting delays and issues faced by children with rarer conditions. MDS is not dissimilar. | [BSH conference item](https://confpartners.eventsair.com/QuickEventWebsitePortal/bsh-2023/bsh-programme/Agenda/AgendaItemDetail?id=079c24d3-2800-4761-bf54-f1ed7f51232f)  [Backlog in NHS genome service leaves families facing long wait for results (The Guardian, April 2023)](https://www.theguardian.com/society/2023/apr/03/backlog-in-nhs-genome-service-leaves-families-facing-long-wait-for-results) |
| 36 | MDS UK Patient Support Group | **Diagnostic tests: Test results**  Key area for quality improvement 4  Improve intra-operability of systems for delivery of diagnostic information of blood cancers – ensuring data can be easily uploaded to the hospital patient records. | The BSH 2023 survey conducted by SIHMDS/Das-Gupta highlighted the discrepancies regarding the format of results – ranging from PDF, emails, letters, Word documents.  There is no easy option to upload the critical and very detailed laboratory results.  Receiving hospitals have to resort to manually input data into patient records, opening up the risk of human error and leading to inaccurate information for the treating haematologist.  As a support group, we regularly receive many calls from patients reporting a lack of precise diagnosis data. | [BSH conference item](https://confpartners.eventsair.com/QuickEventWebsitePortal/bsh-2023/bsh-programme/Agenda/AgendaItemDetail?id=079c24d3-2800-4761-bf54-f1ed7f51232f) |
| 37 | SCM2 | **Diagnostic tests: Test results**  Unexpected Findings  Patients and their GPs have specialist support on how to manage unexpected findings on diagnostic tests. | Unexpected findings are frequent in modern medical imaging, especially for CT. Some findings will be important and many will not. Patients and GPs will require assistance in managing these.  Examples below pertaining to lung cancer screening:  In the West London lung screening pilot, a strict protocol was adhered to for referrals to primary care for non-lung cancer findings. A numerically small proportion (163/1542, 10.6%) of participants attending a LHC were referred to primary care for further management or investigation.  In the NLST and other worldwide clinical trials for lung cancer screening, the rates of significant IFs varied from 1% in the Dutch-Belgian lung cancer screening trial (NELSON) up to 19% at a Canadian center participating in the International Early Lung Cancer Action Program (I-ELCAP). Two recent studies of lung cancer screening programs implemented in the United States reported higher rate of IFs of 40.7%10 and 94%11 though only 2%-13% of patients required further evaluation.  This is an essential part of primary to secondary and back to primary care handover as mentioned in NG138 to manage the unexpected findings from medical investigations. | Implications of incidental findings from lung screening for primary care: data from a UK pilot  Emily C. Bartlett, Jonathan Belsey, Jane Derbyshire, Katie Morris, Michelle Chen, James Addis, Maria Martins, Carole A. Ridge, Sujal R. Desai, Saeed Mirsadraee, Simon Padley, Sarah Whiteside, Pritti Vaghani, Jaymin B. Morjaria, Samuel V. Kemp & Anand Devaraj npj Primary Care Respiratory Medicine volume 31, Article number: 36 (2021)  Incidental Findings on Lung Cancer Screening: Significance and Management  Emily B. Tsai MD ⁎, Caroline Chiles MD †, Brett W. Carter MD ‡, Myrna C.B. Godoy MD, PhD ‡, Girish S. Shroff MD ‡, Reginald F. Munden MD, DMD, MBA †, Mylene T. Truong MD ‡, Carol C. Wu MD  Seminars in Ultrasound, CT and MRI. Volume 39, Issue 3, June 2018, Pages 273-281  https://www.nice.org.uk/guidance/cg138/chapter/1-Guidance#essential-requirements-of-care  1.4 Continuity of care and relationships  1.4.2 For patients who use a number of different services (for example, services in both primary and secondary care, or attending different clinics in a hospital), ensure effective coordination and prioritisation of care to minimise the impact on the patient.  1.4.3 Ensure clear and timely exchange of patient information:  between healthcare professionals (particularly at the point of any transitions in care) |
| 38 | SCM4 | **Diagnostic tests: Test results**  Key area for quality improvement 3  QS1 Direct Access to diagnostic tests.  CT and MRI although there is urgent direct access from Primary care the waiting times for reporting and results appears to be anecdotally lengthy waiting times which appears to be growing. | Perhaps an agreed National expected time for reporting on these tests can be provided as the waiting for these results is an anxious time for patients and their loved ones and we know that if a cancer is detected early the outcome for the individual is greatly improved.  The findings identify avenues for quality improvement activity and provide a baseline for future audit of the impact of 2015 National Institute for Health and Care Excellence guidance on management and referral of suspected cancer. | [Variation in suspected cancer referral pathways in primary care: comparative analysis across the International Benchmarking Cancer Partnership.](https://pubmed.ncbi.nlm.nih.gov/36127155/)  [Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit](https://pubmed.ncbi.nlm.nih.gov/29255111/) |
| 39 | Bowel Cancer (UK) | **Safety netting**  Monitoring patients at higher risk of developing cancer | Some people are at higher risk of developing cancer as a result of family history, ethnicity, age, genetic conditions or other conditions that may lead to cancer eg. Inflammatory bowel disease.  Steps should be taken to monitor these patients so that changes in their health are identified at the earliest possible stage, increasing the likelihood of early diagnosis. | An example of a patient monitoring pathway would be inflammatory bowel disease which increases the risk of developing colorectal cancer  IBD:<https://gut.bmj.com/content/early/2022/09/05/gutjnl-2022-328309.full> |
| 40 | Cancer52 | **Safety netting**  Piggy-back screening for rare and less common cancers in screening tests for more prevalent cancer types | While CT scanning for lung cancer, take a quick look at the abdomen for kidney cancer. While undergoing gynae ultrasound or CT scans, look at the kidneys for kidney cancer. | EXAMPLE: The Yorkshire Kidney Screening Trial (YKST) which investigates the feasibility of developing a full kidney cancer screening clinical trial. People taking part in a pioneering lung screening trial in Leeds were also checked for kidney cancer with an extra kidney scan immediately following the CT scan of their lungs. This added 10-15 seconds to the procedure. <https://www.cambridge-urologicalmalignancies.org.uk/copy-of-yorkshire-kidney-screening-> |
| 41 | SCM6 | **Safety netting**  Safety netting approaches to ensure test requests are followed up and acted upon appropriately | NG12 advocates that test results are reviewed and acted on appropriately. However, many issues can occur after a test request e.g. phlebotomy / imaging appointments missed, stool sample not returned, problems with the sample, results not followed up / actioned.  Some of these issues (including unreturned FIT samples) are highlighted in recent guidelines on FIT testing (Monahan et al 2022), which recommend the adoption of safety netting approaches.  Ensuring that processes are in place so a) cancer test requests are followed up appropriately and b) any issues with tests are identified and acted upon, may improve patient care and diagnostic timeliness. | - NG12 (as discussed)  - Guideline recommending safety netting for FIT samples:  [Faecal immunochemical testing (FIT) in patients with signs or symptoms of suspected colorectal cancer (CRC): a joint guideline from the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the British Society of Gastroenterology (BSG)](https://gut.bmj.com/content/71/10/1939) |
| 42 | SCM5 | **Safety netting**  Safety-Netting | Safety netting in the light of the review and suggestions here:  [https://evidence.nihr.ac.uk/alert/safety-netting-in-general-practice-manage-uncertain-diagnoses/](https://urlsand.esvalabs.com/?u=https%3A%2F%2Fevidence.nihr.ac.uk%2Falert%2Fsafety-netting-in-general-practice-manage-uncertain-diagnoses%2F&e=9f250c40&h=52647e54&f=y&p=n)  (Summary of Friedmann Smith et al, 2022, [Optimising GPs’ communication of advice to facilitate patients’ self-care and prompt follow-up when the diagnosis is uncertain: a realist review of ‘safety-netting’ in primary care](https://qualitysafety.bmj.com/content/31/7/541)) | See left |
| 43 | Target Ovarian Cancer | **Safety netting**  Safety netting for patients with persistent symptoms but whose test results are reported as normal for all cancers not find or engage with us | A common theme in Target Ovarian Cancer’s research around improving diagnosis is the role of safety netting for those who test results are reported as normal but have ongoing symptoms.  With the move to remote consultations and the disbandment of a ‘family GP’ approach to care, robust safety netting is more important than ever. It’s important that primary care recognises and utilises digital safety netting systems that are available to help support recognition and referral. There are different options for safety netting systems available that can be easily integrated into GP IT. For primary care to successfully recommend and implement a safety netting system, the principal focus should be to maintain continuity of the diagnostic pathway across the multiple professionals a patient may see.  Target Ovarian Cancer has worked with Pennine Lancashire Cancer Alliance to develop an approach safety netting by searching through the GP practice system to identify patients with a recent normal CA125 blood test result. CA125 is the initial diagnostic test for ovarian cancer.  These patients can then be clinically reviewed and contacted if required to discuss if symptoms have persisted.  This search was carried out by four PCNs in Pennine Lancashire. 402 women were identified. 365 were contacted and given advice about persistent symptoms and returning to their GP. 100 per cent of respondents found the normal CA125 monitoring a worthwhile exercise for them and their patients. 100 per cent of respondents felt this helped to provide an effective safety netting system for women. The workload was generally reported as positive and manageable.  The safety netting protocol was evaluated positively, and no challenges were identified. This indicates that a review of safety netting practice would be a straightforward task for any PCN or Cancer Alliance looking to improve earlier diagnosis. | Please see [Target Ovarian Cancer’s research into improving early diagnosis – Breaking down barrier to early diagnosis of ovarian cancer 2021](http://www.targetovariancancer.org.uk/breaking-down-barriers-early-diagnosis-ovarian-cancer) |
| 44 | SCM6 | **Cancer site-specific issues: Bladder cancer**  Referral for bladder cancer investigation in patients with recurrent/persistent UTI | NG12 recommends GPs consider referral for bladder cancer in people >60 with recurrent/persistent UTIs.  Recent evidence indicates that those with recurrent UTIs who qualify for a referral experience long intervals before referral (Zhou et al 2023) and longer diagnostic intervals than patients presenting with other symptoms of possible urological cancer (Zhou et al 2021). A sex disparity has also been identified (female sex is associated with longer intervals).  Referral of patients with recurrent UTIs, who meet NICE criteria, could help reduce diagnostic delay in bladder cancer. | Cited studies:  [Identifying targets for improving the diagnostic process of patients with possible bladder and kidney cancer: a mixed-methods study (accepted manuscript)](https://bjgp.org/content/bjgp/early/2023/03/23/BJGP.2022.0602.full.pdf)  [Prolonged Diagnostic Intervals as Marker of Missed Diagnostic Opportunities in Bladder and Kidney Cancer Patients with Alarm Features: A Longitudinal Linked Data Study](https://pubmed.ncbi.nlm.nih.gov/33466406/) |
| 45 | SCM5 | **Cancer site-specific issues: Endometrial cancer**  HRT/ PMB | advice on PMB for women on HRT? | Info not submitted |
| 46 | SCM7 | **Cancer site-specific issues: Endometrial cancer**  Key area for quality improvement 2  Suspected endometrial cancer | Rationale:   * Due to recent media coverage and publicity, there has been an explosion in prescriptions for HRT. The existing NICE (NG12) guidance recommends that all women with post-menopausal bleeding (PMB) should be considered for an appointment with a specialist within 2 weeks. This is causing much concern in Secondary Care due to capacity issues – bleeding on HRT is very common * GPs are very confused as to who they need to refer and clarifications on the NG12 referral criteria via a new quality standard would be much appreciated. It will also lead to more consistent care pathways nationally * Many local pathways recommend that GPs request ultrasound scans for women with PMB on HRT before doing a 2WW referral. If this is safe and evidence-based, could this be included in a new quality standard? * Many GPs do not feel confident in interpreting USS results for endometrial thickness. If local services decide upon the thresholds of normality for endometrial thickness, this may lead to geographical variations and another postcode lottery. A NICE quality standard indicating the thresholds of normality for endometrial thickness (to govern who requires a 2WW referral on HRT) would therefore be much appreciated in Primary Care. The RCOG already has some recommendations on this but I am not sure if they’re still NICE approved. | Supporting Information:   * It would be helpful if the quality standard could align: * NICE guideline NG12 for endometrial cancer * [The NICE accredited RCOG green-top guideline 67](https://www.rcog.org.uk/media/knmjbj5c/gtg_67_endometrial_hyperplasia.pdf) * [The NICE CKS on HRT](https://cks.nice.org.uk/topics/menopause/prescribing-information/hormone-replacement-therapy-hrt/) |
| 47 | Bowel Cancer UK | **Cancer site-specific issues: Lower GI/colorectal cancers**  Testing for blood in faeces | Early diagnosis and prevention of cancer is a key priority for the Government and underpins the ambition of the NHS Long Term Plan.  Cancer waiting times standards have been missed for a prolonged period and continue to deteriorate. qFIT was identified as a suitable quality standard during the last review period (published 2016, updated 2017) and availability is still unequal.  qFIT can, alongside the patient’s clinical features, help GPs and other healthcare professionals decide who to refer based on their risk of having colorectal cancer. It is helpful to understand which patients are at highest risk, so they can be prioritised for further testing.  For patients who are deemed at lower risk it is important to ensure that there are appropriate safety-netting measures in place to ensure adequate follow up as some of them will have cancer.  The rationale for the current standard still holds: “Many colorectal cancers leak blood into the bowel intermittently. Tests for the presence of blood in faeces are relatively easy, inexpensive and safe, and help to identify people at higher risk of having colorectal cancer. People at higher risk can then receive definitive investigation sooner, resulting in earlier treatment for those diagnosed with cancer.” | Since the last review, the British Society of Gastroenterology (BSG) in conjunction with the Association of Coloproctology of Great Britain and Ireland (ACPGBI) published a joint [guideline](https://gut.bmj.com/content/71/10/1939) for the use of qFIT in adults presenting symptoms of suspected colorectal cancer. [FIT flowchart](https://www.bsg.org.uk/wp-content/uploads/2022/05/FIT-Flowchart.pdf) |
| 48 | NHS England Cancer Programme (NCD) | **Cancer site-specific issues: Lower GI/colorectal cancers**  Key area for quality improvement 8  Existing – Site-specific  FIT to all patients with symptoms of colorectal cancer, with only positive results referred on LGI urgent cancer pathway | NICE is currently undertaking a review of its guidance on FIT. We recommend that, should this review recommend that FIT is offered to patients with symptoms of colorectal cancer, then quality statement three should be updated to make explicit reference to this. | Please see the [2022 exceptional surveillance of suspected cancer](https://www.nice.org.uk/guidance/dg30/resources/2022-exceptional-surveillance-of-suspected-cancer-recognition-and-referral-nice-guideline-ng12-and-quantitative-faecal-immunochemical-tests-to-guide-referral-for-colorectal-cancer-in-primary-care-nic-11132498701/chapter/Surveillance-decision?tab=evidence): recognition and referral (NICE guideline NG12) and quantitative faecal immunochemical tests to guide referral for colorectal cancer in primary care (NICE diagnostics guidance 30)  Please see guidance by the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the British Society of Gastroenterology (BSG):  <https://gut.bmj.com/content/71/10/1939> |
| 49 | Roche Products UK | **Cancer site-specific issues: Lower GI/colorectal cancers**  Earlier diagnosis | There is broad consensus that detection and diagnosis of cancer at an early stage provides patients the best chance of curative treatment and long-term survival. For example, 92% of patients with bowel cancer diagnosed at stage 1 survive their disease for at least five years, compared to 10% of patients diagnosed at stage 4. However, in England, for example, just over half of patients are diagnosed at an early stage, demonstrating significant opportunity for improvement.  Roche welcomes the commitment set out in NHS England’s Long Term Plan to detect 75% of cancers at an early stage by 2028.  2022/23 planning guidance priority states that at least 80% of FDS lower GI referrals are accompanied by a FIT result, skin (teledermatology) and prostate cancer (best practice timed pathway).  Lower GI  Currently there is significant variation in direct access to diagnostic tests in all 3 pathways creating inequality of access which may be impacting outcomes.  Evidence around the benefit of FIT testing in primary care has developed significantly (a rare example - aided by the pandemic) and is now supported by the PCN DES which should further support achieving the 80% FIT in primary care ambition.  Skin  Within the skin pathway there is current significant variability in the use of teledermatology in primary care (supported by the GIRFT report). Significant funding has been provided to expand the availability and quality of dermatoscopes to improve access and delivery of the 2 week wait pathway for skin. This is further supported by the PCN DES which states that the British Association of Dermatologists details new models of service delivery for systems to consider. This would aim to optimise the suspected 2 week wait skin cancer referrals, both to help to recover the skin cancer activity delayed as a result of the COVID-19 pandemic, and meet new demand as services are restored.  Skin being a high volume pathway there is merit in considering a rapid appraisal of evidence / benefit of primary care teledermatology skin pathways and developing ‘see and treat’ models that have been developed with a view to understanding and then standardising pathways to reduce variability and improve the pathway overall. Data suggests that currently too many patients are being referred on a 2 week wait skin pathway who have not been fully assessed with teledermatology in primary care. Ensuring that only those with suspected skin cancer (evidenced by teledermatology) need to attend secondary care would significantly reduce the burden in secondary care but will only work with appropriate funding of any primary care services.  We would encourage a focus on earlier diagnosis when looking at additional areas for quality improvement. | [Using Faecal Immunochemical Testing (FIT) in the Lower Gastrointestinal (GI) pathway (NHS England)](https://www.england.nhs.uk/wp-content/uploads/2022/10/B2005_i_Using-faecal-immunochemical-testing-lower-gastrointestinal-pathway_primary-care-letter.pdf)  [Faecal immunochemical testing (FIT) in patients with signs or symptoms of suspected colorectal cancer (CRC): a joint guideline from the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the British Society of Gastroenterology (BSG](https://www.bsg.org.uk/clinical-resource/faecal-immunochemical-testing-fit-in-patients-with-signs-or-symptoms-of-suspected-colorectal-cancer-crc-a-joint-guideline-from-the-acpgbi-and-the-bsg/)):  [NHS Network Contract Directed Enhanced Service Early Cancer Diagnosis Support Pack:](https://www.england.nhs.uk/wp-content/uploads/2022/03/B1357_PCN-ECD-Guidance-SUPPORT-PACK-FINAL_March-2022.pdf)  [Dermatology GIRFT Programme National Specialty Report Aug 2021:](https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/DermatologyReport-Sept21o.pdf) |
| 50 | SCM3 | **Site-specific: Lower GI/colorectal cancer**  Use of qFIT across primary care, prior to referral for suspected cancer | Joint guideline from Association of Coloproctology of Great Britain and Ireland (ACPGBI) and British Society of Gastroenterology (BSG)  People with suspected cancer are still referred from primary care before being tested with qFIT, which then delays the diagnostic pathway  There is strong evidence that this should be adopted throughout primary care. | [Faecal immunochemical testing (FIT) in patients with signs or symptoms of suspected colorectal cancer (CRC): a joint guideline from the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the British Society of Gastroenterology (BSG) | Gut (bmj.com)](https://gut.bmj.com/content/71/10/1939) |
| 51 | SCM7 | **Site-specific: Lower GI/colorectal cancer**  FIT | * What pathway should we still be referring on urgent pathway those who are FIT -ve but fulfil other NG12 referral criteria? Locally gastro A&G or routine gastro referral advised but what about considering ovarian or upper GI pathology? And should this be on a 2WW pathway? * This doesn’t align with the BSG and NHSE backed guidance as specifies patients without rectal bleeding: Quality statement 3: Testing for blood in faeces | Suspected cancer | Quality standards | NICE | No information submitted |
| 52 | SCM7 | **Site-specific: Lower GI/colorectal cancer**  Key area for quality improvement 1  FIT use as part of suspected cancer referral pathways (lower GI and potentially upper GI pathways) | Rationale:   * In the years following the publication of NG12, there has been a seismic shift in how FIT is used in Primary Care, as part of referrals for suspected cancer. My query relates mainly to LGI pathways but recently some upper GI teams have suggested that FIT testing is useful and clinically indicated prior to UGI scoping too – I wonder if there is an evidence base supporting this and if so, would this be reflected in a new NICE quality standard on FIT? * With regards to the LGI pathway and in light of new publications (e.g. the BSG guidance and the latest Cancer Waiting Times guidance) it would be good to ensure that advice to GPs is robustly evidence-based, to avoid patients being unnecessarily held back from a 2WW referral in Primary Care (which could lead to more late-stage diagnoses and emergency presentations). * Based on the current evidence and in light of recent publications (as above) how significant are NG12 symptoms in decisions to make LGI 2WW referrals? * At present, this is a hot topic and there is much confusion in Primary Care. People do not know whether the BSG guidance has superseded NG12. To avoid a postcode lottery in how FIT is utilised, a NICE quality standard would be hugely welcomed & it will hopefully lead to more standardisation of care * Colorectal cancer is the 4th commonest cancer in the UK and the 2nd leading cause of cancer death – the potential to improve patient outcomes through the appropriate use of FIT tests in Primary Care is therefore significant | Supporting Information:  It will be helpful if the new quality standard on FIT could align the following:   * NICE clinical guideline NG12 * NICE clinical guideline DG30 * The BSG guidance (some people say this is NICE endorsed but I’m not sure if it’s the organisation, rather than the BSG guideline on FIT, that is NICE endorsed because the latter conflicts with the NICE guideline, NG12) * The NICE FIT study <https://academic.oup.com/bjs/article/108/7/804/6181760?login=false> * [The FIT literature review, British Journal of Cancer](https://www.nature.com/articles/s41416-021-01653-x) |
| 53 | SCM7 | **Cancer site-specific issues: Lung cancer**  Key area for quality improvement 4  Suspected lung cancer | Rationale:   * The current NICE guideline (NG12) has a huge emphasis on chest x-rays (CXR) but we know that a normal CXR does not exclude a diagnosis of lung cancer. In fact, a BJGP study suggests that 23% lung cancer patients have a negative CXR. In acknowledgement of this, could a new NICE quality standard allow for patients with a normal CXR but high clinical suspicion of cancer to be referred on a 2WW pathway? * Also, in certain clinical presentations, a CXR is not the best diagnostic test to exclude cancer (e.g. patients with unexplained haemoptysis). Increasingly, local areas are commissioning GP access to low dose CT scans within 2 weeks, especially for specific clinical indications where there is a high enough risk of lung cancer. Could this be incorporated into the new quality standard, to ensure patients have equitable access to diagnostics, regardless of geography? If the recommended pathway for GP access to CT chest is via a STT pathway, that would be ideal (please see rationale above) * Lung cancer is a high-volume tumour group and it is the biggest cause of cancer-related death in the UK. In choosing this for a new NICE quality standard, we could have a significant impact on patient care | Supporting Information:  It would be helpful if the quality standard could align:   * NICE guideline NG12 on lung cancer * [Systematic review on CXR sensitivity for lung cancer](https://bjgp.org/content/69/689/e827#:~:text=The%20few%20high%2Dquality%20studies,lung%20cancer%20in%20some%20patients.): * [National optimal timed lung pathway](https://www.england.nhs.uk/wp-content/uploads/2018/04/implementing-timed-lung-cancer-diagnostic-pathway.pdf%20(please%20see%20page) |
| 54 | SCM6 | **Cancer site-specific issues: Ovarian cancer**  Assess/investigate women with a high CA125 but normal ultrasound for other conditions (including non-ovarian cancers) which may be causing their symptoms | NG12 recommends that if a woman has a CA125 ≥35U/ml but a normal ultrasound: “assess carefully for other clinical causes of her symptoms and investigate if appropriate”.  The symptom profile of ovarian cancer overlaps with that of other cancers. CA125 elevations can be caused by different types of cancer. Recent research has shown that in women with an abnormal CA125 test in GP but no ovarian cancer, the risk of other types of cancer is high (12.3% overall and 20.4% of those aged ≥50 years were diagnosed with another cancer within 12 months of an abnormal CA125 test). This has recently been recognised in NHS guidance on implementing the faster diagnostic pathway for gynaecological cancer (advises referral to RDC be considered if CA125 is high but ultrasound is normal due to the high risk of other cancer types).  In summary, new evidence indicates that women with high CA125 levels but normal ultrasound scans in general practice are at high risk of having a non-ovarian cancer. Appropriate assessment and, if necessary, investigation of these women (in line with NG12 guidance) could aid detection of multiple types of cancer. | - NG12 (as discussed)  - [High risk of other types of cancer in women in English General Practice with CA125 ≥35U/ml who are not diagnosed with ovarian cancer:](https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003295)  - Implementing a timed gynaecology cancer diagnostic pathway (highlights further investigation should be considered in this group):  <https://peninsulacanceralliance.nhs.uk/wp-content/uploads/2021/11/Gynaecology-Faster-Diagnosis-Pathway-Guidance-v3.0-FINAL.pdf> |
| 55 | SCM7 | **Cancer site-specific issues: Ovarian cancer**  Key area for quality improvement 5  Suspected ovarian cancer | Rationale:     * The five-year relative survival rates for ovarian cancers in women is below the European average in England, Wales, Scotland and Northern Ireland. * At present, there are only 2 referral criteria for seeing a specialist (ascites and pelvic / abdominal mass – which are more consistent with late-stage presentations). To enhance early diagnosis through a new NICE quality standard, is there scope to broaden the NG12 referral criteria for referrals (either to see a specialist or for investigations) based on new evidence? Is the PPV underpinning the NG12 ovarian cancer referral criteria 3% or is it 3% cumulatively for all Gynae cancers? If the PPV is >3% for ovarian cancer specifically, perhaps this could be lowered based on new evidence, if present? * Also, many GPs do not feel skilled at interpreting USS reports for ovarian lesions. Perhaps a new NICE quality standard could clarify when GPs should refer patients with an abnormal ovarian USS for a 2WW referral to see a specialist, based on existing NICE accredited guidelines (please see right) | It would be helpful if the quality standard could align:   * NICE guideline NG12 on ovarian cancer * [RCOG guidance on management of ovarian masses](https://www.rcog.org.uk/media/yhujmdvr/gtg_62-1.pdf) * [NICE CKS (which contains additional symptoms / factors for Primary Care to consider in relation to ovarian cancer)](https://cks.nice.org.uk/topics/ovarian-cancer/diagnosis/when-to-suspect-ovarian-cancer/) |
| 56 | Pancreatic Cancer UK | **Cancer site-specific issues: Pancreatic cancer**  GPs should refer people over 40 with jaundice for an urgent CT scan | Rapid access to a CT scan upon first presentation of jaundice is needed for earlier and faster diagnosis of pancreatic cancer.  There is currently variation across the UK in access to urgent ambulatory referral pathways for people presenting with jaundice. In addition, there is also variation in the diagnostic test that people receive – with some regions undertaking ultrasound rather than CT scan.  Rapid access pathways for people with jaundice has been shown to increase the number of people eligible for surgery.  (reference:  [Stevenson-Hornby V (2018) A rapid-access diagnostic pathway in suspected](https://cdn.ps.emap.com/wp-content/uploads/sites/3/2018/11/1812-A-rapid-access-diagnostic-pathway-in-suspected-pancreatic-cancer.pdf) )  People presenting with jaundice can also have other conditions diagnosed through a CT scan, therefore, there is wider value to be referred to a CT scan when they present with jaundice. | NICE Guideline 12  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. [2015]  Information from a forthcoming publication was submitted. |
| 57 | NHS England Cancer Programme (NCD) | **Cancer site-specific issues: Prostate cancer**  Key area for quality improvement 6  New – Site-specific  Clinical capacity to support mpMRI prior to local anaesthetic transperineal biopsy for patients referred on urgent suspect cancer pathways | Sufficient clinical capacity should be in place to support mpMRI prior to local anaesthetic transperineal biopsy (LATP biopsy) for patients referred on urgent suspected prostate cancer pathways.  This should include radiology reporting capacity modelled to address demand and also pathology capacity to turnaround biopsy results.  Conducting mpMRI before first prostate biopsy may improve the detection accuracy of clinically significant cancer (PROMIS trial).  In 2015-16, only 51% of men underwent an mpMRI for suspected prostate cancer, of which 73% were performed before biopsy.  Approximately 25% of patients with suspected prostate cancer had a non-suspicious mpMRI and avoided the need for immediate biopsy (PROMIS), with approximately 45% avoiding the need for immediate biopsy in the RAPID programme. This change in practice will lead to a reduction in biopsy-associated risks such as infection.  Using mpMRI before biopsy has the potential to dramatically improve patient experience with a potential ‘rule-out’ of significant prostate cancer without the need for an invasive procedure. | Please see guidance by the NHS Cancer Programme for local health and care systems on implementing [timed cancer diagnostic pathways for prostate cancer](https://www.england.nhs.uk/wp-content/uploads/2018/04/B1348_Prostate-cancer-timed-diagnostic-pathway.pdf), which provides more information on the importance of clinical capacity to support mpMRI prior to LATP biopsies. |
| 58 | SCM5 | **Cancer site-specific issues: Prostate cancer**  PSA | * change to the guidelines around PSA & asymptomatic (or early) prostate cancer. The old association with LUTS is still strong and needs an update. * risk benefit change with initial diagnostics but lack of clarity for over 80y patients and even about testing if no symptoms in over 80. * evidence for case-finding- high risk populations having a diagnosis may do more harm if not necessarily aggressive and would be indolent- is there evidence for higher risk disease in some populations? * very helpful to have some evidence-based uniformity about the management of a modestly raised PSA. Some consultants in departments are asking for a repeat is the first reading is below 10 (others use a different cut off). There seems to be no consistent management pathway across different consultants within a single Hospital Trust let alone across different Hospital Trusts within an ICB | No information submitted |
| 59 | NHS England Cancer Programme (NCD) | **Cancer site-specific issues: Skin cancer**  Key area for quality improvement 7  New – Site-specific  Teledermatology to support skin cancer pathway | Teledermatology services should be available to support the skin cancer pathway to speed up diagnosis, manage high volumes of referrals and reduce face-to-face appointments in dermatology clinics that are not clinically necessary. These services should also be focussed in the community either via a primary care hub or community diagnostic centre.  Teledermatology is the remote assessment of skin cancer using imaging. It has the advance of speeding up diagnosis, reducing unnecessary face to face hospital attendances, and reducing demand in outpatient clinics. Acting quickly in this area is important to provide diagnosis quickly, with benefits to the patient and also to the system to meet 2 week wait and faster diagnosis standard (FDS) requirements. | Please see documents by the NHS cancer Programme and the British Association of Dermatologists on:  [Guidance for local health and care systems on implementing a timed skin cancer diagnostic pathway](https://www.england.nhs.uk/wp-content/uploads/2018/04/B1350_Skin-cancer-timed-diagnostic-pathway.pdf):  [Innovative approaches to support early diagnosis of skin cancer are part of the NHS COVID-19 recovery plan:](https://www.england.nhs.uk/wp-content/uploads/2022/04/B0829-suspected-skin-cancer-two-week-wait-pathway-optimisation-guidance.pdf) |
| 60 | SCM5 | **Additional areas: Central Nervous System and brain cancers**  CNS and Brain cancer | * clarification required something clearer than “progressive subacute focal neurological deficit”, it’s hard for GPs to interpret- anything more concrete? | No information submitted |
| 61 | MDS UK Patient Support Group | **Additional areas: Diagnostics for MDS**  Key area for quality improvement 5 Improve possibilities to diagnose MDS via peripheral blood, rather than a bone marrow biopsy, especially in the very elderly. In many elderly or frail people, the biopsy is not performed, and MDS is diagnosed, but without specifics – hence denying some patients access to potential treatment, as details are not known. | The much elderly patients, a biopsy is an ordeal that they should be spared.  Yet – they need access to proper diagnostics to access the best possible care. Improvements to using peripheral blood for diagnostic purposes would be very useful. Some work has been conducted, but needs further efforts. | No information submitted |
| 62 | Association of Breast Surgery | **Additional area: Prevention**  Lifestyle factors | It would be good to emphasise the positive lifestyle changes, which could reduce the overall cancer risk – i.e. exercise, alcohol intake, weight loss | See the following:  <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6770822/>  <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8540388/> |
| 63 | SCM2 | **Additional areas:**  **Referral to multidisciplinary team after diagnosis**  Onward referral  Patients diagnosed with a malignancy whilst under primary care are reliably and promptly referred into an appropriate Cancer Multidisciplinary Team. | As stated below in a report published by NHS England Cancer MDMs are central to delivering cancer care. With these new diagnostic pathways we must ensure patients find their way to the most appropriate Cancer MDM as swiftly as possible.  Care by a multi-disciplinary team (MDT) has long been the gold standard for patients with cancer. Signalled by the Calman-Hine report in 1995 and mandated by the National Cancer Plan in 2000, the pledge that all patients with cancer would have their care reviewed by an MDT has now become a central part of the cancer pathway.  National data collection:  The Cancer Outcomes and Services Dataset (COSD) records every MDTM as well as care plan. | [NHS England & Improvement: Streamlining Multi-Disciplinary Team Meetings](https://www.england.nhs.uk/wp-content/uploads/2020/01/multi-disciplinary-team-streamlining-guidance.pdf)  [Cancer Outcomes and Services Data set (COSD) - NDRS (digital.nhs.uk)](https://digital.nhs.uk/ndrs/data/data-sets/cosd#:~:text=The%20Cancer%20Outcomes%20and%20Services%20Data%20set%20(COSD)%20is%20a,other%20national%20cancer%20audit%20programmes.)  Several NICE guidelines recommend site specific cancer MDM discussion e.g. lung - [NICE's quality standard on lung cancer QS17](https://www.nice.org.uk/guidance/qs17/chapter/Quality-statements) |
| 64 | Barts Health NHS Trust | **Additional areas: Retinoblastoma guidance**  Key area for quality improvement 1  Use term fundal reflex rather than red reflex | Red reflex is useful in white children and babies. If abnormal, it may represent a cancer (retinoblastoma) or a serious visually threatening condition (eg congenital cataract). However the term suggests that all non-red reflex patients should be referred urgently to a paediatric ophthalmology clinic. Non-white children will have normal non-red reflexes. Another term such as ‘fundal reflex’ should be used. | PMID:21103138    Shows when GPs refer babies and children with abnormal red reflexes, the vast majority are non-white and normal |
| 65 | Childhood Eye Cancer Trust | **Additional areas: Retinoblastoma guidance**  Current retinoblastoma guidance refers to ‘absent red reflex’.  Retinoblastoma  1.12.2 Consider urgent referral (for an appointment within 2 weeks) for ophthalmological assessment for retinoblastoma in children with an absent red reflex. [2015] | Referring to a ‘red’ reflex discriminates against children from BAME backgrounds, in whom the healthy reflex may be orange or even pale. This is leading to over-referral / over-investigation of healthy children from these groups, causing unnecessary distress to families and cost to the NHS.  We suggest using a transitional wording of ‘absent fundal (‘red’) reflex’ until the phrase fundal reflex is more widely recognised, to move away from the misapprehension that a healthy reflex is always red.  The Newborn & Infant Physical Examination guidelines also highlight this point:  “The normal red reflex varies in hue depending on the baby’s ethnicity. White babies have an orange-red reflex. The reflex can be less bright and appear magnolia in colour in black, Asian or minority ethnic babies. If the assessment is difficult, it can help to assess the baby’s parents’ red reflexes to determine the expected reflex colour.” | See:  1. [Newborn and infant physical examination programme handbook – examination of the eyes](https://www.gov.uk/government/publications/newborn-and-infant-physical-examination-programme-handbook/newborn-and-infant-physical-examination-screening-programme-handbook#screening-examination-of-the-eyes)  2. Reflex Test using the Arclight Low-Cost Ophthalmoscope, University of St Andrews <https://www.youtube.com/watch?v=wCdbRxsWa6U> |
| 66 | Cancer52 | **Additional areas: Self-referral** Self-referral for scans on the NHS | If a patient has worrying symptoms that remain undiagnosed by their GP, they are able to self-refer for a CT, MRI, or ultrasound scan. | EXAMPLE: Self-referrals are already available in the private sector. Self-referral options allow people to act by requesting their own scan. They might not even need to see a GP to do this - many Telehealth providers offer remote clinical guidance to complete referrals: <https://uk.scan.com/news/how-do-mri-referrals-work-your-complete-guide-to-gp-referrals-and-self-referrals#:~:text=Self%2Dreferral%20(private%20only),such%20as%20at%20Scan.com>. |
| 67 | SCM5 | **Additional areas: Sensitivity and specificity of diagnostic tests**  Some clarity on statistics and how they arused eg how NHSE are using NPV with it’s shortcomings of using NPV in a low prevalence population are cited in the literature. I’ve had endless conversations before the I&I Fund was amended with a Personal Adjustment for example  "..However, the shortcoming of predictive values is their dependence on prevalence of the condition being tested. If prevalence is low, PPV will be low and NPV high, the converse is also true [23](https://urlsand.esvalabs.com/?u=https%3A%2F%2Fwww.ncbi.nlm.nih.gov%2Fpmc%2Farticles%2FPMC3361685%2F%23R23&e=9f250c40&h=d0a091de&f=y&p=n),[25](https://urlsand.esvalabs.com/?u=https%3A%2F%2Fwww.ncbi.nlm.nih.gov%2Fpmc%2Farticles%2FPMC3361685%2F%23R25&e=9f250c40&h=6c37e654&f=y&p=n). Sensitivity and specificity are less sensitive to prevalence hence they are more reliable measures of diagnostic accuracy..."  [Aliu and Chung (2012), Assessing Strength of Evidence in Diagnostic Tests](https://urlsand.esvalabs.com/?u=https%3A%2F%2Fwww.ncbi.nlm.nih.gov%2Fpmc%2Farticles%2FPMC3361685%2F&e=9f250c40&h=148d10fd&f=y&p=n) | 23. Fritz JM, Wainner RS. Examining diagnostic tests: An evidence based perspective. *Phys Ther.*2001;81:1546–1564. [[PubMed](https://pubmed.ncbi.nlm.nih.gov/11688591)] [[Google Scholar](https://scholar.google.com/scholar_lookup?journal=Phys+Ther&title=Examining+diagnostic+tests:+An+evidence+based+perspective&author=JM+Fritz&author=RS+Wainner&volume=81&publication_year=2001&pages=1546-1564&pmid=11688591&)]  24. Hawkins RC. The evidence based medicine approach to diagnostic testing: Practicalities and limitations. *Clin Biochem Rev.*2005;unpubl:7–18. [[PMC free article](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1252824/)] [[PubMed](https://pubmed.ncbi.nlm.nih.gov/16278748)] [[Google Scholar](https://scholar.google.com/scholar_lookup?journal=Clin+Biochem+Rev&title=The+evidence+based+medicine+approach+to+diagnostic+testing:+Practicalities+and+limitations&author=RC+Hawkins&volume=26&publication_year=2005&pages=7-18&pmid=16278748&)]  25. Simel DL, Samsa GP, Matchar DB. Likelihood ratios with confidence: Sample size estimation for diagnostic test results. *J Clin Epidemiol.*1991;44:763–770. [[PubMed](https://pubmed.ncbi.nlm.nih.gov/1941027)] [[Google Scholar](https://scholar.google.com/scholar_lookup?journal=J+Clin+Epidemiol&title=Likelihood+ratios+with+confidence:+Sample+size+estimation+for+diagnostic+test+results&author=DL+Simel&author=GP+Samsa&author=DB+Matchar&volume=44&publication_year=1991&pages=763-770&pmid=1941027&)] | See left |
| 68 | RCGP | Advised no comment at this stage. | N/A | N/A |
| 69 | RCN | Advised no comment at this stage. | N/A | N/A |
| 70 | RCR | Advised no comment at this stage. | N/A | N/A |