

Cancer: earlier diagnosis and quality improvement

Mr Khan is 58 and an ex-smoker. Eight weeks ago, he had presumed COVID-19, diagnosed on a telephone consultation. At that time, he reported a 7-day history of cough and dyspnoea. He had no high-risk features and was advised to self-manage. Unfortunately, he wasn't able to get a confirmatory test. Three weeks later, he spoke to a colleague to say he wasn't feeling much better. He calls back today reporting that it is still difficult to climb a flight of stairs, he can't get back to work and he hasn't much appetite.

What would you do?

In the UK, significant progress has been made in the past decade in improving rates of early diagnosis and treatment for cancer patients. But the impact of the COVID-19 pandemic has been wide ranging, and one of the unintended consequences of lockdown and the temporary change in delivery of health services has been the impact on cancer screening and diagnosis.

As this article goes to press (June 2020), after 10 weeks of lockdown ([CRUK Science Blog June 2020](#)):

- 2 million people are waiting for cancer screening, tests and treatment.
- For every week the cervical, breast and colorectal screening programmes are paused, 380 cancers are not being diagnosed.
- 290 000 fewer individuals have been referred via urgent two-week-wait pathways. This is largely because they are not presenting in primary care, but may also be because we are reluctant to refer or because diagnostic services, e.g. endoscopy, have been put on hold.
- Fewer patients have had surgery and chemotherapy.

In addition, Early Diagnosis now has its own QOF domain, and many of us are participating in the PCN DES, one aspect of which focuses on earlier diagnosis of cancer. This article is designed to be a useful resource to support this work and, more importantly, our patients.

Should we still be following existing guidance for suspected cancer referrals?

Yes, absolutely.

In England and Wales, NICE NG12 still applies. Direct correspondence with Prof Willie Hamilton who chairs the NICE suspected cancer: recognition and referral guideline committee reports that there is no intention to produce interim guidance to further risk-stratify patients. We should follow NG12 as our gold standard and refer as we always would have done.

In Scotland, SCRG should still be followed, and the Northern Ireland Cancer Network recommends continuing to refer based on existing guidance.

What if my referral is downgraded?

- Document that the patient has been referred on an urgent pathway but the referral has been downgraded.
- Communicate and explain this to the patient.
- Check that contact details are up to date.
- Safety-netting is particularly important both clinically AND medicolegally in this situation:
 - Set a proactive reminder to review with patient whether symptoms have resolved, persisted or worsened.
 - Encourage the patient to report if their symptoms worsen or persist beyond an explicit, agreed timeframe.

Early diagnosis pitfalls

Remote consulting, less continuity of care and fewer visual clues means we have to work harder and more deliberately to spot those low-risk but not-no-risk symptoms that may be pointing to an underlying cancer. *Some of our 'GP Jedi sense' of seeing the patient in front of us and getting that 'something isn't right' feeling may be missing when we see people remotely.*

A BJGP article identified recurrent themes in delayed diagnosis (BJGP 2017;67(659):276). These are pertinent because they remind us of situations where we could all easily miss a cancer. Let's consider these themes and then what we can do to reduce the chance of delayed diagnosis.

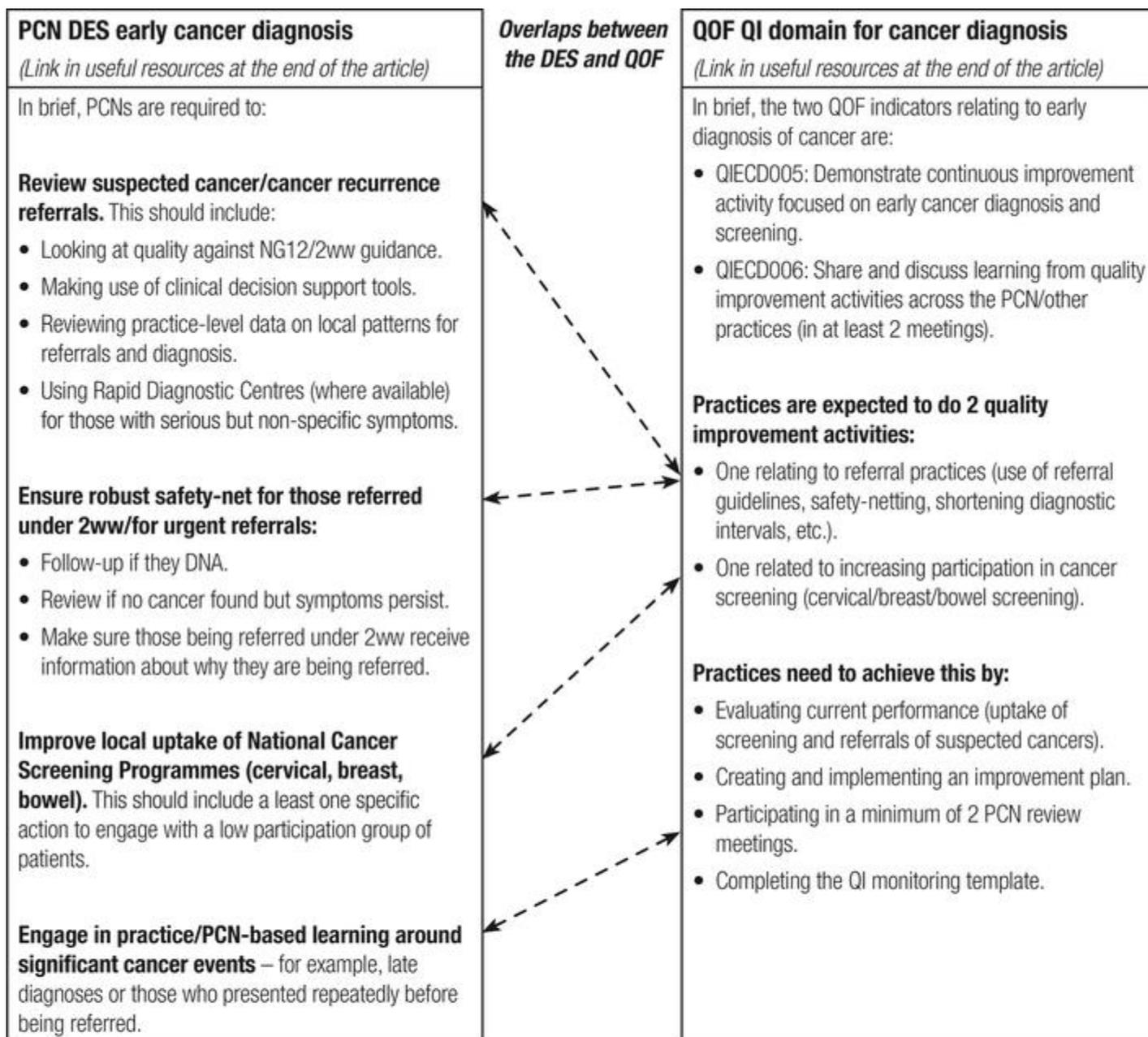
Think of these things in terms of 3 categories:

- Red flags that are easily missed.
- False reassurance from investigations.
- Safety-net failures.

Red flags that are easily missed ('camouflaged' red flags!)	
Persistent/recurrent infection	<p>This is a common scenario where a cancer may be missed – particularly if the patient is seen by a range of clinicians or in a range of settings. Specific examples to consider include:</p> <ul style="list-style-type: none"> • Recurrent exacerbations of COPD, particularly if this is a change in pattern: think – <i>could this be lung cancer? Also, in the current climate, be wary of clinically-diagnosed COVID-19 that then persists. While we are seeing this in clinical practice, we need to consider, could this be something else, e.g. PE or lung cancer?</i> • Recurrent urinary tract infections and non-resolving microscopic haematuria: think – <i>could this be bladder cancer? Do you have a system in place to spot and follow this up?</i>
Constant pain	<p>Most 'benign' pain, e.g. musculoskeletal, comes and goes, and varies in intensity, nature and with position.</p> <ul style="list-style-type: none"> • If pain is constant and unchanging (or just getting progressively worse), consider malignancy, e.g.: <ul style="list-style-type: none"> ◦ Shoulder/chest wall pain for lung cancer. ◦ Mid-back pain for pancreatic cancer. ◦ Deteriorating back pain in older patients for myeloma or metastatic prostate cancer. ◦ Abdominal pain for colorectal cancer.
Vague symptoms, multiple consultations	<p>The most common reason for multiple consultations is diagnostic difficulty, particularly for poorly-differentiated symptoms (BMJ 2014;349:g7400).</p> <ul style="list-style-type: none"> • Cancers that had multiple consultations were the 'harder to spot cancers', e.g. myeloma, pancreatic, lung, small intestine, liver, gallbladder and stomach. • In a study of 7000 patients diagnosed with rarer cancers, the number of consultations required to get this diagnosis was remarkably consistent across a whole range of geographical areas (BJGP 2016;66(644):e171). <p>Recent research around softer markers of cancer, e.g. thrombocytosis, weight loss and 'low-risk but not-no-risk symptoms', is helpful in this area and can be read elsewhere in the handbook.</p> <p>The '3-strikes-and-in' rule may also be helpful for appropriate patients.</p> <p>In many areas, Rapid Diagnostic Centres (RDCs) are offering pathways that help investigate these patients more rapidly and efficiently. RDCs allow patients with vague symptoms that would not meet any particular 2ww pathway to be investigated in a streamlined manner.</p> <p>It is estimated that if GPs refer to an RDC with a suspicion of cancer, they will turn out to be correct for 16% of patients (<i>this is great!</i>). Other diagnoses are also made.</p> <p>A recent evaluation of the Welsh pilot of RDCs tells us that (BJGP 2020;70(692):e186):</p> <ul style="list-style-type: none"> • They reduce the length of time to get a diagnosis (cancer or non-cancer) from 84 days to 6 days on average if all investigations can be done on the day. If they can't, diagnostic time is still more than halved to 40 days (<i>even better!</i>). • They are cost effective provided they run at 80% capacity. <p>So, we should use these if we have them. And if we don't have them, we could phone a friendly secondary care colleague/radiologist etc. but the pathway is unlikely to be as simple. Hopefully, we will soon all have access to Rapid Diagnostic Centres.</p>
Unusual age for diagnosis	<p>Don't exclude cancer as a possible diagnosis purely on the basis of age – young or old!</p> <ul style="list-style-type: none"> • Young patients get cancer – the incidence of colorectal cancer in the under-50s is increasing significantly (see article on <i>Colorectal cancer</i>). • In older people, beware of making a new diagnosis of a condition that usually first presents at a younger age, e.g. IBS, migraine, mechanical back pain. In the atypical age range, <i>don't make a clinical diagnosis</i> – investigate! • Trust your gut – if the age is wrong but the symptoms are worrying, investigate.
Infrequent attenders who start attending	<p>Infrequent attenders who suddenly start to attend are at higher risk of a serious diagnosis.</p> <p>There is a small body of evidence, and a much larger body of experience, to support this.</p> <p>If you don't already, have a low threshold for investigating this group. And beware of missing them if you operate a total triage system with less personal continuity – deliberately look out for, and look harder at, infrequent attenders.</p>

False reassurance from negative investigations	
Clinicians falsely reassured by investigations	<p>Clinicians and patients can be falsely reassured by negative investigations – but the truth is, there is <u>no perfect test</u> in primary care to rule out cancer.</p> <ul style="list-style-type: none"> • Particular examples clinicians should be aware of are: <ul style="list-style-type: none"> ○ Chest X-rays – will miss one-quarter of lung cancers (BJGP 2019;69(689):e827). ○ Ovarian cancer: CA125 followed by ultrasound if CA125 abnormal (as per NICE guidance) will only pick up 66% of ovarian cancers (NICE 2015;NG12). ○ PSA: 1 in 7 men with a normal PSA will have a prostate cancer (PCRMP National Screening Committee 2016). <p>So, if symptoms persist or the investigations don't sit comfortably with our gut feeling, we should investigate further, or at least safety-net carefully. It is also important how we communicate these results.</p>
Patients falsely reassured by investigations	<p>Patients are also falsely reassured by negative tests:</p> <ul style="list-style-type: none"> • Patients who have screening tests or 2ww investigations and who are given the 'all-clear' change their consulting behaviour. <p>A BJGP study of people who had undergone urgent investigations showed that:</p> <ul style="list-style-type: none"> • Nearly half of all patients waited more than 3 months to report further alarm symptoms. • Most patients took comfort from the 'all-clear' when they got new symptoms, even if these appeared in a completely different part of their body! • Many patients trusted that the tests had ruled out anything serious going in their <i>entire</i> body. • Some worried they would be wasting the doctor's time or be seen as a hypochondriac, and experienced anxiety, fear and embarrassment about re-presenting. • A trusted relationship with their GP made it more likely they would seek help (BJGP 2016;66(644):e158). <p>A reminder of the importance of safety-netting! (more on that later!)</p>
Safety-net failures	
Inadequate safety-nets or safety-nets not used by patients	<p>Good safety-netting involves clear advice to patients, and relies on patients remembering and acting on the advice given. This can go wrong either at the clinician's end or the patient's end.</p> <p>Good safety-netting is an essential part of managing risk and uncertainty in primary care. However, while widely acknowledged to be good practice, there is an absence of evidence as to whether safety-netting improves cancer detection, or indeed how best to do it, but this evidence base is growing.</p> <p>A UK-based qualitative study that looked at more than 300 recorded GP consultations found that safety-netting advice was given for 2/3 consultations but was often not specific and not documented – so there is room for improvement (BJGP 2019;69(689):e878).</p> <p>An Oxford-based qualitative study of GPs demonstrated that while most were supportive of optimising safety-netting, many doubted the feasibility of informing patients of negative test results or flagging the notes of individuals with recurrent unexplained symptoms given current workload and time constraints (BJGP 2019;69(689):e819).</p> <p><i>Later in this article, we consider strategies that might help, and this could be a good area to look at as part of Early Cancer Diagnosis Guidance DES.</i></p>
Inadequate safety-nets to follow-up those who do not attend urgent appointments	<p>5–7% of symptomatic referred patients cancel or do not attend their hospital appointment. Subsequent rate of cancer diagnosis is lower in this group, but in those who do get diagnosed, mortality rates are higher.</p> <p>A UK-based qualitative study explored reasons for this (BJGP 2019;69(689):e850). They were wide ranging but included:</p> <ul style="list-style-type: none"> • Social deprivation/difficult lives. • Older age. • Difficulties for patients (and GPs) in navigating the referral system, e.g. very short notice. • Communication issues within the consultation. • Errors in contact details. <p>There was significant variation in how non-attendance was followed-up depending on systems/time pressure and individual clinical perception of where responsibility lies.</p>

What do we need to do for the PCN DES and QOF?



If you are taking part in the PCN DES or QOF, or just want to improve cancer care in your practice, we strongly recommended you use the Macmillan toolkits for early diagnosis and screening. Links can be round in the resources section at the end of the article. They walk you through the process, give you the searches you need and make things as painless as possible!

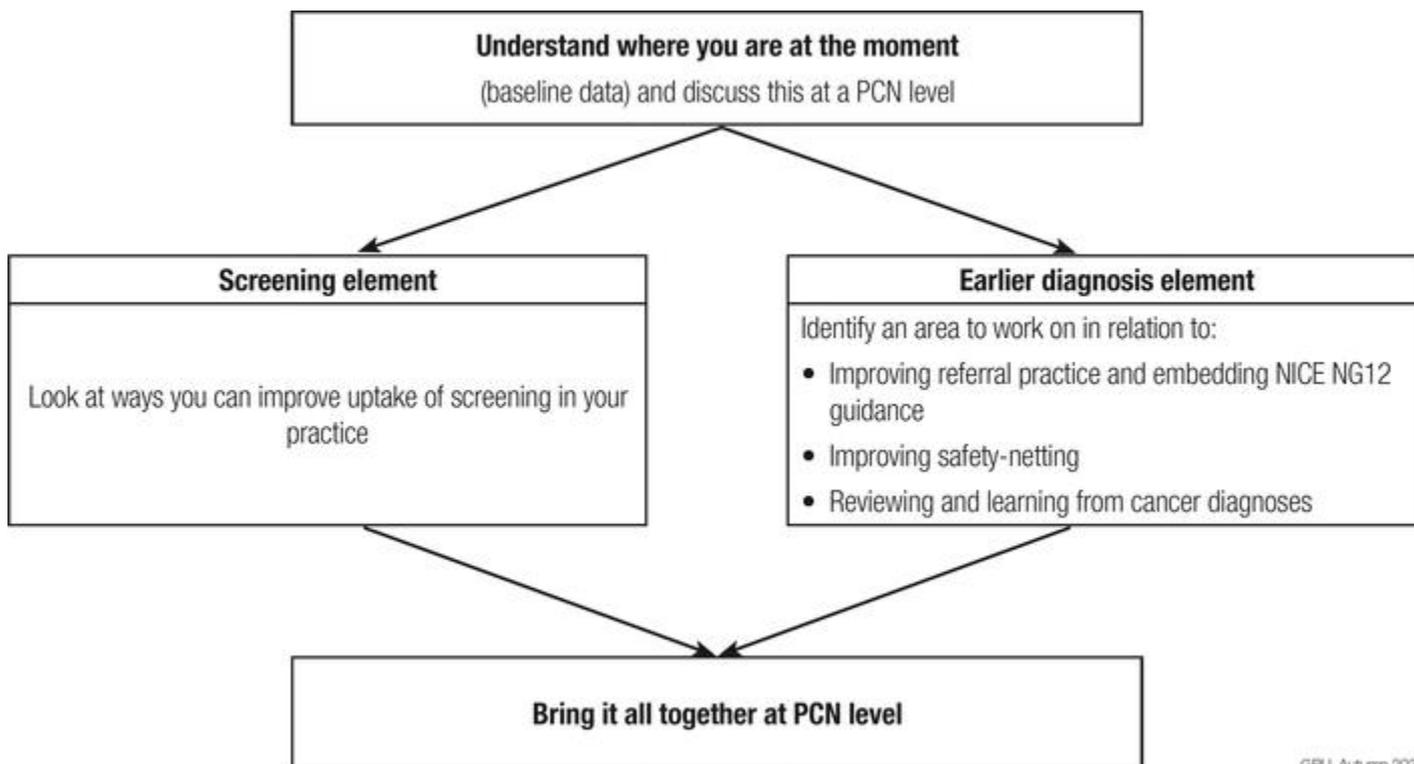
And remember, it doesn't need a GP to do it all: use other members of your clinical and administrative teams to help you out!

So, what do we actually need to do?

We recognise that all practices and PCNs are at different places and have different resource and capacity. Here we offer ideas if you are feeling low on energy and inspiration. You do NOT have to do them all and please feel free to go your own way!

Remember, it does not necessarily have to be a GP who leads this project – if another member of the team is a passionate advocate for cancer care, could you support them in having the time to take a lead on this?

We see this as involving a series of steps:



GPU_Autumn 2020

In the following sections, we have broken these down into more detail; all hyperlinks can also be found in the resources section at the end of the article.

Baseline data

Ideas

None of us have time to reinvent the wheel – so understanding where you are at now, what you do well and where there is room for improvement is a great start. As a baseline, ask yourself these questions (suggestion below on where to get the data you need for some of the answers!):

Screening

- What are our baseline rates of breast, bowel and cervical screening? How do we compare with others locally and with the national picture? Do we have a policy to identify non-attenders?

Early diagnosis

- How are we implementing NICE NG12 in our practice/PCN? Is the information as accessible as possible? Does every clinician have access and understand how to use it?
- Are we using a cancer decision support tool?
- What are the routes of referral for new cancer diagnoses? Is everyone aware of local direct access diagnostics, the availability of Rapid Diagnostic Centres, etc.?
- What are our current safety-netting procedures? Do we all do the same?
- Is there a robust system to ensure:
 - Patients referred by urgent suspected cancer route are seen?
 - The results of direct access diagnostics are seen and acted upon?
 - Patients with low-risk but not-no-risk symptoms are appropriately followed-up?
- Do all patients referred on an urgent suspected cancer pathway receive a patient information leaflet from the practice? Do we code that this has been given?
- What proportion of patients with a new cancer diagnosis do we currently do SEA/LEA (Learning Event Analysis) for?

From this, you can probably identify:

- Areas you are doing brilliantly: perhaps other practices in your PCN would be interested to hear about your systems and learn from what you are currently doing.
- Areas which you are already doing well: perhaps a small tweak could make things even better, and wouldn't take a huge amount of effort....
- Areas where you realise things could be done better: perhaps a simple small change may have great rewards, or you may have the energy to overhaul a larger bit of the system...

Possible actions and resources to support you

Remember, the Macmillan tool will walk you through this process and has the searches within it!

ACTION: Identify baseline data on screening and referral at practice level, PCN level and CCG level here:

<https://fingertips.phe.org.uk/profile/cancerservices>

The **Macmillan toolkit** and **Screening toolkit** highlight and provide simple downloads to all the searches you need to run to provide the data to answer the questions in the ideas column. These work in EMIS, SystmOne and INPS Vision.

ACTION: Audit at least 20 consecutive cancer diagnoses or a random sample of at least 20 cases over the previous 12 months (use searches from Macmillan toolkit or, if you have taken part in the National Cancer Diagnosis Audit, you can use relevant data from this – these searches will enable you to look at the routes of referral these patients took).

ACTION: If, as part of this, you identify patients where the referral or diagnosis process could have gone better, e.g. diagnosis as an emergency presentation or a routine referral, retain the details to review as part of Learning Event Analysis (see below).

Having completed this process, the baseline data should be shared with the whole practice team and used to create an 'improvement plan'.

TIP: Include non-clinical staff: they may be invaluable in offering process suggestions, and you are more likely to get buy-in!

Screening element: improving local uptake of National Cancer Screening Programmes

Ideas

You may already be participating in local programmes to improve uptake in certain groups or for certain screening programmes.

Remember, endorsement of screening by family doctors can improve uptake.

Possible actions and resources to support you

ACTION: Consider regular searches for non-responders. Use telephone calls rather than letter to contact them. **This script** may be useful for non-clinical staff to use for bowel cancer screening (see link in useful links section).

ACTION: Explicitly promote screening programmes, e.g. 'Don't fear the smear' or 'Bowel cancer screening saves lives' cards.

Early diagnosis element (3 parts: referrals, safety-netting and learning)

Improve referral practice and embed NICE NG12 guidance

Ideas

Your actions in this area may depend on whether you are a high or low referring practice. Options may include:

- Make NG12 easier to access and refer to.
- Make NG12 easier to use, e.g. use digital clinical decision support tools. The tools highlighted have been developed based on UK primary care data – they **rely on coded symptoms, signs and investigations**. They identify absolute risk of a possible cancer diagnosis based on the available data, and some make recommendations for next steps. They can be used to:
 - Decide whether to investigate further/refer using NICE PPV 3%.
 - Support decision-making in vague presentations.

At a local level, these tools can be seen to increase the number of patients investigated and referred on cancer pathways, and more cancers are diagnosed. However, there is an absence of robust evidence to CONFIRM that these tools are responsible for the improvements seen in cancer diagnosis in the past decade (BJC 2015;113:1615).

- Consider taking part in the National Cancer Diagnosis Audit.
- If you have a Rapid Diagnostics Centre, ensure everyone is aware of it, who can be referred, pathways, etc., and track number of referrals after the educational intervention.

Possible actions and resources to support you

ACTION: Enable access to a summary of the NICE guidelines.

- [Macmillan desktop guide](#).
- [CRUK poster infographic](#).

ACTION: Start using a digital cancer decision support tool during consultations, e.g.:

- [Macmillan CDS](#) can be freely integrated into all primary care computer systems.
- Q Cancer is embedded in EMIS.
- [C the Signs](#) can be used on multiple platforms and has been commissioned in some CCG areas.

ACTION: Improve the efficacy of cancer decision support tools by improving quality of coding. For example, use symptom codes as well as diagnosis codes, e.g. abdominal pain, weight loss. You may want to review and agree coding good practice. This [resource](#) may be helpful if this is an area you want to work on.

ACTION: Increase our referral rate. If we work at a 'low referring practice' with less good outcomes, we need to reframe what makes us feel like 'good GPs'. Our role as gatekeepers has meant that for some of us, an urgent referral that does not translate to a cancer diagnosis was seen as a failure. This is not true. Give yourselves permission as a team to refer more – good cancer outcomes correlate with high referral and low conversion rates (BJGP 2017;67(669):276).

Build on current safety-netting practices

Ideas

The objective here is to:

- Increase the proportion of suspected cancer referrals where a robust practice-wide system for safety-netting is used.
- Improve the information provided to patients at the time of referral.

Safety-netting has 3 key features with respect to early cancer diagnosis – to ensure:

- Attendance at appointments following urgent referral for suspected cancer (and to spot and follow-up non-attendance).
- The results of investigations are received and acted on appropriately.

- That people with symptoms that could be associated with cancer but who do not meet the criteria for referral or investigation are counselled and reviewed appropriately.

Possible actions and resources to support you

ACTION: Make sure there is a process of checking contact details before making a referral for every suspected cancer referral.

ACTION: Create a pathway to ensure patients receive all test results (even negative ones), with an explanation of what this means and when to reconsult.

ACTION: Give all patients being referred on an urgent suspected cancer referral pathway written information. You may have local leaflets; alternatively, suitable resources include:

- [Healthy London Partnership \(multiple languages\)](#).
- [CRUK 'Your urgent referral explained' cards](#).

ACTION: Code that this information has been given:

- EMIS 80AQ.
- SystemOne XadFZ.
- SNOMED 988781000000100.

ACTION: Develop a practice-wide policy for coding and follow-up processes to ensure a robust digital safety-netting process.

You can make use of this [Safety-netting toolkit](#). Otherwise, the [London Cancer and MacMillan: Guide to quality coding and safety-netting in the context of cancer](#) may be helpful.

Review cancer diagnoses: learn from both when things go well/could have gone better
Ideas

An example of a SMART objective here might be: *We will increase the % of new cancer diagnosis cases that we review and learn from by 5% to 10% over the next 6 months.*

Possible actions and resources to support you

ACTION: Implement SEA/LEA for all cancers that present as an emergency or where there were multiple presentations before referral. If you are already doing this, consider looking at other groups, e.g. routine referral pathways or specific cancers.

You could use [Macmillan/RCGP toolkit and template](#) to support the process of SEA/LEA.

ACTION: Discuss these as a practice team.

Turning the tap back on after COVID-19

The final and perhaps hardest piece of the jigsaw at this present time in the midst of COVID-19 is 'turning the tap back on', and getting patients to trust the system and their safety so that they still present with persistent worrying symptoms.

The Be Clear on Cancer campaign that has run over the past 10 years had contributed to an increased willingness of people to come forward with symptoms that 'might' be a cancer, e.g. persistent cough, change in bowel habit or blood in stool, persistent heartburn, dysphagia, abdominal bloating, skin changes and haematuria.

As individuals, practice teams and collectively as primary care, we could:

- Refresh and promote the message that the NHS is still open for business.
- Remind people of those symptoms that should be assessed.
- Build confidence that people can safely be seen in primary care, and that there are safe places in hospitals to have investigations.

We can do this through clear communication with our patients via our websites, receptionists, community posters, patient participation groups, etc; make it clear that symptoms still need to be seen, and that there are measures in place to protect people and staff from COVID-1