

# Early diagnosis and cancer treatment

How system working can help get the NHS back on track

## Key points

- Cancer services and screening continue to be severely affected by the COVID-19 pandemic and the NHS will be dealing with the backlog for some time to come. This effect has varied across the country and across different cancer areas.
- There is recognition from partners working within systems that clear, aligned communication with the public is key. This should reiterate that the NHS is there when needed. Building confidence around the safety and availability of GP and diagnostic services is crucial if more cancers are to be detected at an earlier stage.
- Restored services have to be sustainable enough to cope with future waves of COVID-19 and the demand on primary care of the vaccination programme. In the next few months, it may not be possible to both restore cancer services and continue with less urgent operations at the level NHS England and NHS Improvement wants to see.
- Collaborative working can help improve cancer care, but more needs to be done to understand what models work best. For example, cancer alliances cover different configurations of integrated care systems. Local areas need to be able to escalate problems they cannot solve to higher levels.
- This briefing sets out a number of recommendations, including for NHS England and NHS Improvement to commission research on how effectively cancer alliances are working together with integrated care systems and sustainability and transformation partnerships, with a focus on the impact of different configurations and what good practice looks like.

## Background

The COVID-19 pandemic has had a significant impact on cancer services. Much elective work has been postponed, including some cancer operations and treatments. In many areas some screening services temporarily stopped.

COVID-19 also reduced the likelihood that cancer would be picked up in patients presenting in other parts of the health service. Many hospitals saw A&E attendances drop to the lowest level since records began, with people reluctant to attend because they feared catching COVID-19. Fewer patients contacted their GPs and it is likely that the opportunity was missed to refer those with possible cancer symptoms for further investigation.

Potentially, the numbers affected are huge. More than 3 million people across the UK would have been due to have cancer screening in this period and thousands of others with symptoms of cancer would have been picked up in A&E or GP surgeries, Macmillan Cancer Support argues in [The Forgotten 'C'? The Impact of COVID-19-19 on Cancer Care](#). It estimates the number of patients with undiagnosed cancer at 50,000 higher than in previous years and says that 30,000 fewer people started cancer treatment between March and August 2020 than in the same period in 2019.

Urgent cancer referrals did increase in the autumn of 2020, but there are variations with referrals for lung and urological cancers still well below levels a year ago. Some patients with vague symptoms, rather than the more obvious signs such as breast lumps, may also not have sought medical advice because of a reluctance to visit GPs.

NHS England and NHS Improvement has made restoring cancer services to full operation as soon as possible a priority, but there will be challenges in tackling the backlog of screening and diagnosis and many people will be diagnosed with more advanced cancers as a result of the delays in the first part of the pandemic. This may mean an impact on their health for years to come, as they may require more aggressive interventions, and in some cases it may mean their lives will be shortened. The impact of the second wave of COVID-19 in the autumn and third wave over winter is unclear, but it could have led to further delays in diagnosis. In the early

autumn it seemed the cancer system was coping quite well, using several of the tactics learned from the summer and the difference this made initially. But this changed dramatically with the emergence of the more infectious strain.

A roundtable, organised by the NHS Confederation and MSD (funding provided), brought together healthcare professionals, service managers and patient and charity representatives to look at key obstacles to restoring full services and dealing with this backlog, what solutions can be found and how improved system working could help. This briefing is based on what was discussed at the roundtable.

## The problem

The [Macmillan Cancer Support report](#) paints a bleak picture for cancer services:

- 50,000 'missed diagnoses' and urgent referrals in August 2020 still 11 per cent below 2019 levels
- cancer services needing to increase to well above pre-pandemic levels to address both diagnostic and treatment backlogs
- infection control issues in some diagnostic areas, such as endoscopy, have reduced the number of patients who can be seen when the NHS needs to increase capacity above pre-pandemic levels in order to reduce backlogs.

But even restoring cancer services to the pre-COVID-19 position would mean some patients would not get timely treatment. The 62-day target of GP referral to treatment was a challenge for many health economies, with English performance [below 80 per cent](#) for the whole of 2019/20, and there were acknowledged bottlenecks, such as access to endoscopy after positive qFIT tests. There were also shortages in certain staff groups, which impacted on the ability to meet demand.

The time that will be needed to restore services and catch up with the backlog of work is uncertain; potentially this will take several years to address. There are already indications that performance on early diagnosis has slipped and more cancers are being diagnosed at a later stage.

Older people have been disproportionately affected by the delays in cancer diagnosis and treatment. There is some evidence they were less likely to present to their GP during the first stage of the pandemic and may have been less inclined or able to use alternative consultation methods, such as video. They also have higher levels of concern about coming into contact with COVID-19 through visiting a healthcare facility. Some cancers where services have been most affected during the pandemic tend to disproportionately affect older patients, such as urological cancers. Cancer is also more prevalent in older people, which has meant that the people it affects the most were engaging the least.

There may also be a particular issue with lung cancer, where coughing could have been mistaken for a COVID-19 symptom. Referrals remain below those in 2019.

The NHS nationally is encouraging people to come forward for cancer screening and to seek GP assistance if they have symptoms that might be cancer. But this does not address the capacity issue for GP practices.

As has been demonstrated by the latest national lockdown, the situation remains volatile. Solutions for these problems will need to be sustainable and potentially cope with further disruption during 2021, including the threat of a further wave of COVID-19; lockdowns and local restrictions; and the vaccine rollout requiring time and input from many NHS staff. It is likely that primary care will have delivering the vaccine as the main priority for much of the first half of 2021, which may reduce its capacity to deal with other patients.

The way the NHS reacted to COVID-19 was remarkable, but it involved standing down other services in a way that could not be sustained in the medium term. The challenge now is to devise a plan that both copes with surges of COVID-19 and the workload associated with mass vaccination, and enables critical services, such as cancer diagnosis and treatment, to continue.

## How collaborative working could help address the issue

Cancer pathways stretch from primary care to tertiary services. The solutions to the current issues won't all lie at one point and will need collaboration at different levels. While patients need to be at the centre of this, it may not be possible to always meet their desires. For example, not every treatment can be provided locally and sometimes they will need to travel for treatment in a COVID-19-free environment.

One of the issues affecting all parts of cancer pathways is the 'fear factor.' Patients have always been fearful of being told they have cancer and may not want intrusive and sometimes unpleasant procedures and investigations, but now they are also fearful of visiting a healthcare setting or using public transport to get there. Over the last 12 months, this has meant many have not sought medical help.

Working across a system has offered ways to deal with some of these issues.

### System working in practice

- During the first wave of the pandemic, some hospitals were designated as cancer hubs, carrying out operations for a wider area in a COVID-19-free environment. This meant cancer services could continue at much reduced risk to cancer patients. Retaining such hubs will require several parts of the system to work together.
- In December 2020, MSD in partnership with Northern Cancer Alliance and Greater Manchester Cancer Alliance, alongside UK Lung Cancer Coalition (UKLCC), Lung Cancer Nursing UK, Roy Castle Lung Cancer Foundation and Mesothelioma UK, launched the 'Do It For Yourself' campaign – a multi-channel communications campaign across key areas of the north of England to promote early cancer detection. The campaign recognises that we have become a nation of 'DIYers' during lockdown and that people might want to prioritise their health as they would do fixing up their homes. The sooner a crack is mended the better. [Advertising and PR](#) were run across transport and outdoor poster sites, radio and in pharmacies.

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- The nationwide [Help Us Help You campaign](#) has emphasised the need to seek medical advice for cancer symptoms. This has been promoted locally by clinical commissioning groups (CCGs).
- The Dorset Cancer Partnership has worked with primary care networks to identify patients most at risk of having unidentified lung cancer. Funding has been provided through a local enhanced service for practices, with support to help them identify these patients, along with resources to stop chest X-ray services being overwhelmed. Only one primary care network (PCN) out of 18 has not taken this up.
- Endoscopy has high cancellation and did-not-attend rates, yet is vital for some cancer diagnoses. Some areas have addressed this by getting clinical nurse specialists or consultants to ring patients who intend to cancel, to explain the benefits of the procedure. This has helped to persuade some patients, but not all, to attend.
- During the second and third waves, there has also been extensive use of private sector capacity.

There are likely to be other opportunities for collaborative working going forward:

- Proposed diagnostic hubs, which are likely to cover several primary care networks and may offer tests only previously available in acute hospitals. As they will be on a non-COVID-19 site, this may help to build confidence to attend for tests.
- A greater role for NHS 111 in guiding patients who are concerned about potential cancer symptoms to the right advice. For example, in primary care or, for more urgent cases, booking a slot in A&E. This may need to overcome patient perceptions of the value of calling NHS 111 and the nature of the advice received.
- More 'vague symptom' clinics to investigate patients who present in primary care with non-specific symptoms rather than the more definitive ones associated with cancer, such as breast lumps.
- GPs having direct access to more investigations, such as CT scans for lung cancer, where delays can have an impact on outcomes for aggressive forms of the cancer. There is good evidence that GPs don't overuse diagnostic services when allowed access in this way.

But any changes to cancer services need to ensure patients still get the support they need, which might be the involvement of a clinical nurse specialist or psychological support.

Some issues, such as staffing, may need to be addressed on a larger scale where it would be impossible for individual NHS organisations to address a shortage of specialist staff without poaching from others. Integrated care systems (ICSs) may be able to address this, but some solutions lie at regional or even national level, such as influencing postgraduate and undergraduate education.

Gaps in capacity may also need to be addressed at cancer alliance level, such as using the independent sector to provide additional endoscopy services across its footprint.

Cancer alliances play an important role in much of this, but how can they maximise their impact? They do not always follow the boundaries of specialised commissioning areas, CCGs or ICSs.

In some cases, co-terminosity does seem to have brought benefits. Kent and Medway, where the alliance has the same footprint as the STP and the CCG, has seen a dramatic improvement in cancer performance over the last two years. But others taking part in the roundtable felt that it was impossible to map everything at an ICS level and there were advantages in having differing footprints, though cancer alliances needed to be woven throughout ICSs' work.

## Key asks and roles of different stakeholders

There is no one size fits all answer to how stakeholders should work together and what role each should play. The exact details of this are likely to be dependent on local situations.

However, some general principles emerged from the discussion:

- Issues should be addressed at the most appropriate level, but there should be a mechanism to escalate them upwards when place or neighbourhood services are unable to find an answer. Workforce issues are a good example of this as they may require working at cancer alliance, regional or even national levels to address shortages. The cancer community across the public, private and third sector needs to come together to lobby for what it needs to improve services, staffing and treatment for patients.

- The user voice needs to be heard at all levels: neighbourhood, place and system. At the moment, there can be a gap around patient involvement at the system level.
- While there is no desire to see an overly prescriptive approach taken by the centre, the national lung cancer optimal pathway has shown the value of clinically supported models that can be adopted locally to speed implementation. These should be developed for other cancers. The national Cancer Recovery Plan published in December 2020 is a welcome step.
- Understanding the local population will be crucial in improving outcomes. This applies at all levels but granularities and variations may emerge, such as in the reasons why communities are not accessing services.
- Where extra resources are available, such as the diagnostic equipment promised in the Spending Review, local flexibility in where and how money is used will be important.
- There is a need for understanding between stakeholders of each other's pressures and constraints. If primary care has a low conversion rate from two-week referrals to patients being diagnosed with cancer, this can often be seen as over-referring by those in secondary care. But the evidence is that GPs who refer more have a lower mortality rate and fewer late presentations among their patients.



## Conclusions and recommendations

The NHS faces some difficult decisions and potentially trade-offs as it tries to restore cancer care, while also continuing with non-urgent elective work and coping with COVID-19.

But this time also offers opportunities to think about the optimum model for cancer services in each locality and to introduce changes that will benefit patients and improve outcomes.

While there is no single model of how cancer alliances relate to ICSs and other parts of the system, there are opportunities to learn from work done in different areas and refine how relationships work most productively.

One looming change for cancer alliances is the legislative changes for integrated care systems that are expected to be introduced in 2021. These will embed the 'system, place, neighbourhood' approach.

How cancer alliances fit into this will be important and needs to be considered before the legislation is drafted.

### Recommendations

1. Services should be patient-centred, with high priority given to support for the patient's psychological and emotional needs, as well as their medical ones.
2. Pinch points in cancer pathways that lead to unnecessary delays in diagnosis and treatment for patients need to be examined urgently and solutions found. For example, the additional spending on diagnostics could be targeted on these.
3. While services are still recovering, there is a need to prioritise those patients most at risk from continuing delays. All systems should develop ways of interrogating patient data to identify them.
4. Services for some cancers have been more disrupted than others during the pandemic. Special attention should be paid to how to restore these and this is likely to need tailored solutions. National guidance on pathways for some cancers has been a valuable tool in improving services: NHS England and NHS Improvement should consider whether this approach should be extended to more cancer areas.

5. A multi-year investment is needed to address some of the issues around cancer diagnosis and treatment. While last this year's announcements were welcome, much more is needed and pressure needs to be kept up to ensure that sufficient resources are available.
6. Alternative sites for diagnostic tests should be developed, where possible, as they can keep patients out of acute sites and may encourage attendance among those who are concerned about catching COVID-19 in hospital.
7. There should be a continued focus on communication with the public on the importance of seeking help for any unusual or worrying symptoms. This is particularly important while some patients continue to be reluctant to access medical care. This could help to reduce the number of late presentations.
8. NHS England and NHS Improvement should commission research on how cancer alliances and ICSs/STPs work together, with a focus on the impact of different configurations and what good practice looks like in each of them. This could guide future decisions on co-terminosity and governance.
9. All areas need to develop diagnostic capacity to meet the demand from cancer patients based on GPs referring in line with NICE guidance (outlined in NG 12). GPs should not be put under pressure to refer fewer patients because of capacity gaps, provided they are referring appropriately.
10. Direct referrals from GPs to diagnostic tests can cut time off pathways for some cancers, allowing diagnosis at an earlier point and potentially improving outcomes. The value of this should be assessed. Direct access to CT scans for lung cancer should be one of the first to be assessed.

### About NHS Reset

COVID-19 has changed the NHS and social care, precipitating rapid transformation at a time of immense pressure and personal and professional challenge. One message from leaders and clinicians across the UK has been clear: we must build on the progress made to chart a new course.

NHS Reset is an NHS Confederation campaign to help shape what the health and care system should look like in the aftermath of the pandemic. Recognising the sacrifices and achievements of the COVID-19 period, it brings together NHS Confederation members and partners to look at how we rebuild local systems and reset the way we plan, commission and deliver health and care.

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