



COVID-19 and Cancer: A 12-point plan for restoration, recovery and transformation of cancer services

Introduction

COVID-19 is an unprecedented crisis which has had a profound impact on health and care services across the UK and will continue to have an impact for the months and years to come. To guide the restoration of services, 25 cancer charities have come together and developed this document to set out a '12-point plan', supported by available data and intelligence, for what we believe the health service in England will need to do to enable cancer services to recover from the pandemic.

Cancer is the leading cause of death in the UK, and cancer doesn't stop because of a pandemic. Before COVID-19 there were around 306,000 new cases of cancer in England each year, and sadly, around 135,000 deaths. Early diagnosis followed by swift access to the most effective treatment remains as important as ever for survival. And ensuring someone with cancer has a personalised, holistic experience of their care remains essential for quality of life. The ambitions set out in the Long Term Plan remain critical if we are to see cancer early diagnosis, survival and care in this country match that of the best performing countries.

Around two million people in England are currently waiting for cancer screening, further tests or cancer treatment according to an analysis by Cancer Research UK. At a time when the NHS will be recovering from one major health crisis, we are in danger of creating another, a cancer crisis.

Many cancer patients have experienced new anxieties during this crisis, stemming from uncertainty about when their treatment and tests might get back on track, as well as the risks they face from COVID-19. Around 200,000 people with cancer in England have also been advised to 'shield' and their practical needs – ensuring they have access to food, or considering how they can continue to work – have been suddenly thrown into question. For many people with cancer, this has resulted in social isolation, anxiety and other psychological needs that must be addressed in any recovery plan.

Furthermore, emerging evidence is showing that the pandemic is exacerbating existing health inequalities, placing a greater burden on those from deprived communities and those from BAME groups. People from the poorest communities are at increased risk of exposure to COVID-19 and more likely to suffer negative outcomes. These communities also face inequality at every stage of the cancer pathway. Higher rates of overweight and obesity are experienced in the most deprived areas, and the emerging evidence of increased risk of adverse COVID-19 outcomes for obese or morbidly obese people furthers the case for more intervention to support balanced diets and healthy weight. With any action taken, consideration must be given to improve equity in access to and delivery of cancer services.

There is much work underway to consider how we restart cancer services, locally and at national level, in the shorter term. We would urgently like to see a national vision and plan published, detailing how the Government and the NHS intends not only to manage cancer services over the next few months as we attempt to control COVID-19, but critically how we fully recover services and get back on track to deliver transformed cancer outcomes. Without a clear national vision and plan, progress on cancer survival and care in this country could stall.

We have set out below a 12-point plan across the two phases of the pandemic that NHS England are planning for, restoration (phase II) and recovery (phase III). Across all of these recommendations close monitoring and adequate action is needed to ensure inequalities are addressed. In addition, we have set out plans to get the significant transformation agenda for

cancer services back on track, as simply restoring to pre-COVID-19 levels and models of service is not sufficient to deliver the improved outcomes that patients in this country expect and deserve.

Restoration, expected to last until August 2020

Keeping baseline services running

1. We need to ensure there are clear data available about the scale of disruption to cancer tests and treatment over the past 4 months. Setting out the baseline of how many interventions were postponed or cancelled will allow local services to plan for how they will surge their capacity to catch up. As the UK could face multiple waves of COVID-19 cases, governments and health services should prepare for these scenarios, with a view to keeping fundamental healthcare services running as much and as safely as possible. Plans for redeploying workforce, revising clinical pathways, maintaining COVID-protected spaces, and managing a growth in backlog should be put in place with a view to achieving a safe and efficient baseline provision of diagnosis and treatment services during future COVID-19 peaks.

- a. Steps must be taken to identify and act on learnings from the pandemic's impact on the health service to-date.**
- b. This should include putting in place plans for maintaining a baseline provision of cancer diagnosis and treatment services during any future COVID-19 peaks.**

Covid-protected environments

2. It is vital that safe spaces, protected from COVID-19 as far as possible, are established and maintained in healthcare settings so that cancer patients and patients with suspected cancer can receive care as safely as possible. This is especially important due to the increased risk to many cancer patients from COVID-19. Frequent COVID-19 testing, combined with adequate PPE, infection control and enhanced safety procedures are essential to making this possible.

COVID-19 testing of all patients and healthcare staff – whether symptomatic or asymptomatic – who are based in COVID-protected environments should take place regularly and rapidly. There must be a strategy and sufficient capacity in place to enable this. As a guide, a Cancer Research UK analysis indicates that approximately 21,000 – 37,000 tests per day would be required to test all patients requiring cancer diagnostics and treatment and all staff providing diagnostic and treatment services at a frequency of once per week across the UK¹. Therefore, the Government and NHS should:

¹ Note, this assumes that throughput is back to pre-pandemic levels.

- a. **Develop a robust national strategy for rolling out testing amongst healthcare workers, setting out the order of priority of different parts of the service. Staff and patients in COVID-protected spaces must be identified as high priority so that cancer services can be delivered in environments as far as possible free from COVID-19.**
- b. **Maintain clear national guidance for establishing COVID-protected spaces. This should cover protocols for testing staff and patients, set out requirements for patients to self-isolate before elective procedures, and set out the need to track exposure to individuals (staff or patients) who test positive for COVID-19.**
- c. **Where testing is already happening, ensure access at the point of care is widely available with a rapid turnaround for results (within hours, rather than days), and expand NHS testing capacity so that healthcare workers can be tested at least twice a week (based on the latest emerging thinking)¹, but ideally more.**
- d. **Ensure that there is an adequate supply of PPE for all cancer workforce staff, to protect them from infection and the risk of contaminating COVID-protected cancer hubs.**

Diagnosis and referrals

3. The number of people being urgently referred for suspected cancer² dropped by around 75% at the worst of the coronavirus outbreak, meaning many fewer people being referred for diagnostic tests and specialist consultation. This meant up to 2,300 cancers a week were not being diagnosed via that route, potentially contributing to a shift towards later stage, inoperable disease. A significant proportion of cancer patients are diagnosed following routine referral and our intelligence suggests that these numbers have also reduced significantly. The number of urgent suspected cancer referrals is now steadily improving thanks to national efforts but remains lower than usual, and the backlog of patients requiring diagnostics tests continues to build. Public awareness campaigns should be funded as a priority and developed to encourage people to seek help appropriately and speak to their GP:

- a. **Messaging out to the public needs to improve, be amplified and maintained, so that people with potential cancer symptoms, and where appropriate those at highest risk of a specific cancer, are encouraged to seek help from health professionals. Additional investment into cancer awareness campaigns is needed to maintain this activity and the associated impact.**
- b. **In the short term these campaigns would benefit from a broader message which helps to address the fear that people may have about coming forward (such as fear of COVID-19 infection, but also fear of overburdening the service or wasting the GP's time). This should be kept under review and re-focused as necessary, including consideration of particular cancer types and of cancer screening.**
- c. **Campaigns should be targeted to reduce inequalities and reach deprived communities who bear a greater burden of cancer incidence. There should be local/regional tie-in and coordination to support the reaching of communities most in need.**
- d. **Some GPs are reluctant to refer due to the perceived risk of sending patients into hospitals whilst COVID-19 infection remains high. GPs need clearer guidance and support to refer,**

² Via the 2 week wait

Personalised care

4. A confirmation of the existing national commitments in the Long Term Plan to deliver fully personalised care that meets people's full range of physical, emotional and practical support needs should be explicit in both local and national plans. Failing to identify and support people's needs will result in poorer outcomes and experience for people living with cancer and may result in greater pressure on the health and care system later if unmet needs become more severe or reduce individuals' ability to self-manage their health.

We also know that for some people with cancer, they will sadly need to access palliative and end of life care. These services have been disrupted and their capacity has been put under huge strain. We would like to ensure that end of life services are able to move forward with additional support in future.

- a. **All people diagnosed with cancer (including those under the age of 25) or experiencing changes to their treatment and support should have access to a Holistic Needs Assessment (HNA) or Electronic Holistic Needs Assessment (eHNA), a care plan and the health and wellbeing information necessary to meet their needs. The NHS should work in partnership with cancer charities in the development of this tailored information.**
- b. **Personalised care, including a care coordinator and personalised care and support plans, is a key mechanism to support not only those in the clinically extremely vulnerable group, but all people with cancer who are shielding because of Covid-19, by keeping them updated on their treatment, facilitating access to hospital, primary and community services, supporting emotional needs and helping to meet any additional needs that they may have.**
- c. **The implementation of personalised stratified follow-up (PSFU) pathways tailored to individual needs offers huge benefits to patients and the NHS. Stratified pathway follow up should be prioritised and implemented. We have seen some moves towards this as a pragmatic approach during the COVID-19 pandemic which is welcome, but it must be done well and tied to Health Needs Assessments and personalised care planning.**

Clinical trials

5. COVID-19 has significantly reduced the UK's ability to run clinical trials, with the number of new patients being recruited on to UK-based trials falling by 95% in April 2020 (vs. April 2019). Many studies have been paused. We welcome publication of the National Institute for Health Research's (NIHR) Framework outlining the preconditions for restarting a clinical trial and the criteria for prioritising which trials should be restarted first. However, we are concerned that this Framework will disproportionately benefit commercial, late-phase, and COVID-19 research. We do, however, recognise this is just a first step to restarting clinical research and we look forward to further engagement with the NIHR on its Restart Framework.

- a. **The NIHR should expand level 1 prioritisation to include urgent non-COVID studies, especially studies that provide safer alternative treatments in a COVID-19 environment.**
- b. **The NIHR Restart Implementation group should provide further detail on how they will monitor the balance of trials being restarted (according to sponsor, complexity, and phase) and what measures they will use to remedy any imbalances they identify.**

Supporting the vulnerable

6. During the pandemic, hundreds of thousands of people living with cancer have been advised to shield because they are clinically 'extremely vulnerable' if they were to contract COVID-19. They must receive clarity about this advice from the wider government and receive ongoing and appropriate support for their broader needs whilst shielding.

Many thousands more have felt vulnerable and reluctant to increase their risks of exposure. This may have led to some people with cancer reducing interactions with the NHS, with estimates suggesting that 7% of people postponed treatment themselves³.

As cancer services get back on track, it's incredibly important that everyone living with cancer receives clear, tailored messages from their health and care professionals so they can feel safe and confident when accessing the care and support they need.

- a. **Government guidance for people who are shielding must be developed in an open and transparent way with early engagement and insight from charities, patient organisations and health and care professionals. This will help ensure that people who are shielding can have an informed conversation with their clinical team about what these changes mean and can be empowered to make personal decisions on levels of risk they would be comfortable with. The guidance should move towards a more tailored approach based on an individual's risk, such as age, ethnicity and overall fitness levels. Any reasons for changing guidance should also be published, and advice provided for those loved ones supporting patients at this time e.g. parents of children with cancer.**
- b. **As lockdown restrictions are relaxed, people who are shielding or vulnerable, or live with someone who is, will be facing increasing anxiety about returning to work. The Government must do more to ensure employers are offering furlough to people where returning to work would require them to breach public health advice.**
- c. **Many people with cancer who have been asked to shield, whilst managing a cancer diagnosis, will come out of the pandemic with high levels of unmet psychological need. Services must be planned to manage this need both during and after COVID-19.**
- d. **A longer term roadmap is needed to set out the way forward for individuals who are, and will likely to continue to be, shielding. This needs to be accompanied by clear, consistent and timely communications around key milestones, and a package of support that meets people's physical, psychological and practical needs. It should also ensure that patients with specialist needs continue to receive the right level of specialist care, even when this is delivered at home or digitally. The impact of new models of care on patient experience and quality of life must be monitored.**

Preventing cancer

7. Smoking continues to be the biggest preventable cause of cancer, illness and death in the UK. Recent research suggests that people who smoke who contract COVID-19 are more likely to experience severe symptoms than non-smokers. Smoking also causes a significant burden to the

³https://www.understandingsociety.ac.uk/sites/default/files/downloads/general/ukhls_briefingnote_covid_health_final.pdf

health service: in England alone, there are almost 500,000 smoking-attributable hospital admissions each year.

Given this, it is important that people who smoke continue to be provided with professional support to give them the best chance of stopping smoking, to reduce their risk of cancer, reduce their risk of poor outcomes from COVID-19, and to reduce demand on a stretched health service. Therefore:

- a. Specialist stop smoking services should continue to offer behavioural support and medication to quit, with support delivered virtually.**
- b. National and local governments should ensure that specialist stop smoking services receive proper investment so that everyone who smokes can access specialist support to help them quit.**
- c. Primary and secondary care should provide Very Brief Advice (VBA) on smoking to all patients to encourage and support people who smoke to stop, and act by referring people to local stop smoking services, prescribing medications and/or discussing e-cigarettes as a tool to quit.**

Recovery, expected to run from August 2020 until March 2021

Workforce

8. Action must be taken to increase and retain the staff working in cancer care. This should include standing down the redeployment of surgical teams (including anaesthetists) from COVID-19 work, in order to resume their cancer focus. The cancer charity sector has long been campaigning for more investment in our cancer workforce which we believe is vital to progressing cancer survival in the UK. Before the COVID-19 crisis there were around 1 in 10 diagnostic posts unfilled across the health service. Unfortunately, workforce capacity has become all the more acute, due to the substantial backlog of demand that has built up, service provision becoming more intensive and time-consuming, and risks of workforce attrition due to staff burnout and the impact of COVID-19 on their wellbeing. Action must be taken in the short and longer term to address these issues:

- a. **A clear understanding from the health service of the impact of COVID-19 on numbers of staff in specific cancer professions – including the wellbeing, resilience and morale of staff - and a commitment to address accordingly.**
- b. **Health services should take steps to increase workforce where there is demand, by calling on the independent sector and those who are retired to offer support for the short term.**
- c. **Health services should upskill our existing workforce in skill areas in which a shortage is expected. For example, it is clear that we will need more staff with intubation and intensivists skills because many staff with these skills have redeployed to treat COVID-19 patients.**
- d. **Health services should consider how to use its existing staff and technology as efficiently as possible. Through the adoption of the best ‘skill mix’ approaches, health services can ensure that cancer staff are always using their full range of skills to the good of their teams, ensuring less staff time is wasted and thereby helping alleviate demand. This will also help establish a more flexible, sustainable and resilient workforce in the longer term.**
- e. **Consideration should also be given as to how to best and safely exploit technology to improve efficiency – for example, use of software to carry out mammogram readings in the breast screening programme and in lung CT management.**
- f. **As a priority, health services at a national level should assess diagnostic capacity available for COVID-protected sites and identify any remaining gaps of which diagnostic services cannot be provided within COVID-protected sites.**
- g. **Local decision-makers should put in place processes to coordinate capacity on an appropriate geographical scale. This should be supported by appropriate workforce and resource planning, based on the reality of reduced capacity due to safety requirements and reduction in workforce.**

Screening programmes

9. All national cancer screening programmes in the four UK nations have been de facto paused, which means up to 1.2 million invitations to take part in the bowel, breast and cervical screening programmes are not being sent out each month. Normally, at least 1,600 patients go on to have a cancer diagnosed through the screening programmes each month in UK, mostly at an early stage, with an additional number of potentially pre-cancerous changes diagnosed and treated.

- a. **The Government and the NHS must develop plans – including appropriate communications – to ramp up screening services, including support to primary care and adequate catch-up approaches, with clear targets in place for when to reach pre-COVID levels of coverage and uptake.**
- b. **The national approach to roll-out a programme of Lung Health Checks, separate to the national screening programmes, should also be restarted.**

Guidance

10. Guidance issued by the NHS and Government on the clinical management of cancer patients has rightly set out changes and new considerations which have had to be introduced during the pandemic. Many of these will need to remain in place, but it is important guidance continues to be updated in response to the changing situation.

Updated guidance must reflect the reality of a substantial backlog in treatment demand, and patients’ anxiety about if and when their planned treatment will be able to restart. Extra

resource may be needed to deliver this consistently across the UK. Updated guidance should include:

- a. **Clear expectations about how any alterations to patients' (pre-COVID) planned treatment should be decided and discussed with patients, including how disease progression over this period will be assessed and factored into decision-making.**
- b. **Provide clarity on the priority to be given to meeting performance targets through this phase, given the need to consider how to balance the backlog with new patients coming through the system. Priority should be given to actions that will most improve outcomes and quality of decision-making. This must take into account the impact of treatment delays on those living with secondary incurable cancers to ensure people do not miss out on time with their loved ones.**

Innovation

11. There is also an opportunity to scale up beneficial innovations developed during the initial response and 'lock in' best practice adopted during this period. Much of this has been driven by individual clinicians and amplified through sharing with each other and with charities.

- a. **We need a coordinated programme of activity, across the Cancer Alliances, to highlight local examples of innovations in primary care, diagnostics and treatment delivery which may be suitable for adoption across a wider range of Trusts.**
- b. **There has been real flexibility and pragmatism in the approach to speeding up access to some treatments during this period, this should be built upon going forward.**

Transformation of cancer services to deliver significantly improved cancer outcomes

Long-Term Plan ambitions

12. The Long Term Plan for the NHS in England, published in January 2019, contains a number of ambitions for cancer services that – if met – would deliver significant improvements in survival and patient care. The reason cancer was a priority in the Long Term Plan is that we know we can do better for patients in this country, deliver outcomes that matter and compare favourably with those seen anywhere in the world. Before COVID-19 hit we were not on track to meet the ambitions of the Long Term Plan: we anticipate that over the coming months progress will inevitably stall further. But this doesn't mean we should lose sight of the intent behind those ambitions and update the nation's plan for transforming cancer services:

- a. **A group of independent experts, including insight from patients, should be convened to reassess how to achieve world-class ambitions for cancer outcomes.**
- b. **The Government should take the earliest opportunity to invest in growth in the training and education of the cancer workforce – as any transformation in services will have to be delivered through an adequately resourced workforce for the future.**
- c. **A full assessment of how other countries' cancer services have been impacted by COVID-19 should be carried out.**



The role of cancer charities

Cancer charities have played a key role throughout this crisis in providing services and patient support, as well as helping to communicate messaging to people affected by cancer. Improved understanding and acknowledgment of the role of such organisations is key to ensuring the health service recovers as swiftly as possible. Unfortunately, charities providing vital services to people with cancer and their families are under immense pressure to continue services whilst experiencing a reduction in income. As such, consideration should be given to the prospect that charities will have to reduce the support they provide if they cannot recover from this incredibly challenging financial situation.



This document was developed and published by the organisations listed above in June 2020.

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