



# THE FORGOTTEN 'C'?

The impact  
of Covid-19  
on cancer care

October 2020

**MACMILLAN**  
**CANCER SUPPORT**

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# Foreword

Lynda Thomas, Chief Executive



The Covid-19 pandemic that has gripped the UK since March has set an unprecedented challenge to our way of life and the safe delivery of health care is no exception. Six months ago cancer services across the UK responded with astonishing speed and professionalism to minimise the impact on cancer treatment, ripping up the rule book overnight to adapt, delivering new service models and working together to prioritise those with greatest need.

We're proud of and grateful for our health care professionals who went above and beyond to care for patients in the midst of great fear and uncertainty. Sadly, despite these best efforts, the impact of Covid-19 on people's cancer outcomes and experience of care has been and will continue to be profound. For some, devastatingly, it will be catastrophic and life limiting. Rightly, the NHS pulled out all the stops to care for people with Covid-19. But our new analysis has found that there are 50,000 people now missing a cancer diagnosis who are at risk of becoming the forgotten 'C' of the coronavirus crisis.

We are deeply worried about these many thousands of people who have cancer but have not yet been diagnosed because they are too frightened or too worried to visit their GP; because they are waiting too long for investigative tests; or because they haven't received an invitation to routine screening. We also know there are many people waiting anxiously for their first treatment to start, as well as those who already have a cancer diagnosis and are in need of crucial follow up scans, tests and treatments.

As we go into winter with Covid-19 cases surging it is essential that governments across the UK and NHS leaders learn the lessons from what went wrong during the peak of the first wave of the pandemic. We can't make the same mistakes again. Put simply, cancer doesn't stop for Covid-19 and neither can our health services. Our analysis shows that even with significant extra resource (over and above pre-pandemic levels), it will take 20 months to clear the backlog in cancer diagnosis. We – and many thousands of people with cancer – are deeply concerned that a second surge of Covid-19 could increase this timeline even further.

We are calling on governments across the UK to acknowledge the scale of the cancer backlog and commit the additional resource required to tackle it. We also ask Ministers and the NHS to urgently confirm that vital cancer services will be protected through ringfencing of their staffing and Covid-protected spaces throughout the second wave of the pandemic, and to promise every person living with cancer that they won't be the forgotten 'C'.

# Foreword

Rosie Loftus, Chief Medical Officer



From the moment the pandemic started, healthcare professionals began to consider the untold impact that the disruption to health services would have on their patients. We had little understanding of how long disruption to cancer treatment and care might go on for or what all the consequences might be but we were certain of one thing; cancer patients' needs did not stop for the pandemic.

One Macmillan Cancer Lead Nurse described the fears of many: 'I was worrying about the cancer patients and them getting their diagnosis because everything just stopped. And I'm still worrying about that now, will we ever catch up? Will there be too many late diagnoses? We're going to be in for an explosion and how are we going to manage that?'

Across the system, health and care professionals have done everything they can to respond to an indescribable challenge. Many have upskilled, retrained, returned to practice or taken on new responsibilities on top of everything else, to try to keep services running wherever possible for their patients. The pressure has been immense, and I worry for the wellbeing of even the most resilient of colleagues.

As Macmillan professionals, we will do all we can to respond to the challenges of the coming months, but we really can't do this on our own. This report sets out the urgent action that governments across the UK, Ministers and decision makers must take now to beat the backlog and ensure that cancer services and professionals can continue their vital work in the difficult months and years ahead.

Together, we can and must stop cancer becoming the forgotten 'C'. Cancer patients simply cannot afford for their treatment to be delayed or disrupted any longer. By accepting the recommendations set out in this report and taking the necessary action now, governments and decision makers can ensure they don't have to.

# Natasha's Story

**I was diagnosed with secondary breast cancer in May 2016, when I was 23. I knew the reality of secondary breast cancer is that I would be on treatment for life and I will have to have scans every three months to monitor where the disease is at.**

In March of this year I was on a line of chemotherapy, and I was lucky to have been able to continue having chemotherapy throughout the pandemic, even though it felt different with restrictions meaning I couldn't have my partner with me, I'd got used to that.

The difficulty was I was due to have a scan the week lockdown happened, and that was cancelled with no reason given other than Covid, and I wasn't given a timeframe as to when I would get a scan again. Because I was getting treatment at a different hospital than the one where I had my CT scans, neither me or the chemotherapy team knew how long I'd have to wait.

Nearly five months on from the last scan I'd had, the hospital called me and asked me to come in the next day for a scan. Then I went into a panic, had something shown up in my bloods? Why was I suddenly being called in so quickly when no one had said anything for weeks? I was just told it was because the hospital was in a better Covid situation than before, and were able to get people through.



**Natasha, diagnosed with cancer at 23**

By the time I got my scan the cancer had grown again, and it showed the chemotherapy was not working. I don't know when the cancer had started to grow again but I can't help but think my treatment plan could have changed much sooner to combat the growth had the scan not been cancelled due to coronavirus. Would it not have been as much of a growth if we'd been able to target it sooner? That's what's always going through my head now.

My scans since then have been on time. But going into winter, with cases increasing, I'm just hoping that delays won't happen again.

# Introduction

Throughout the Covid-19 pandemic national policy guidance across the UK set out first that urgent cancer services should be protected from disruption; and then, when it became clear that services had nevertheless been impacted, clear expectations that they should be recovered to near normal levels at rapid pace.

There has been a significant drop in people seeing their GP, and then getting referred for cancer tests – which is now being tackled through the ‘Help Us, Help You’ campaign encouraging people to come forward if they have symptoms. Despite these promises, efforts and directives from governments and NHS leadership there appears to be a disconnect with reality on the ground and a continuing ‘gap’ in cancer care in 2020.

Backlogs in diagnosis and treatment have developed, to varying degrees, across the UK. It is not clear the NHS in all nations can meet the challenge they have been set, nor is it clear that governments have provided the additional resource needed for cancer services to ramp up capacity to meet pent up demand and reduce the backlog. This is set against the worrying backdrop of rapidly rising Covid-19 cases across the UK.

In this report Macmillan sets out the scale of the backlog to cancer care across the UK and the results of our original modelling to assess how long it could take to return to ‘normal’ pre-pandemic service levels. We also shine a light on the experience and stories of people living with cancer during the pandemic. People who have told us how frightening it is to have treatments, tests and appointments cancelled and disrupted, and how worrying it is to feel abandoned within the health system.

To give voice to people living with cancer in this report, we:

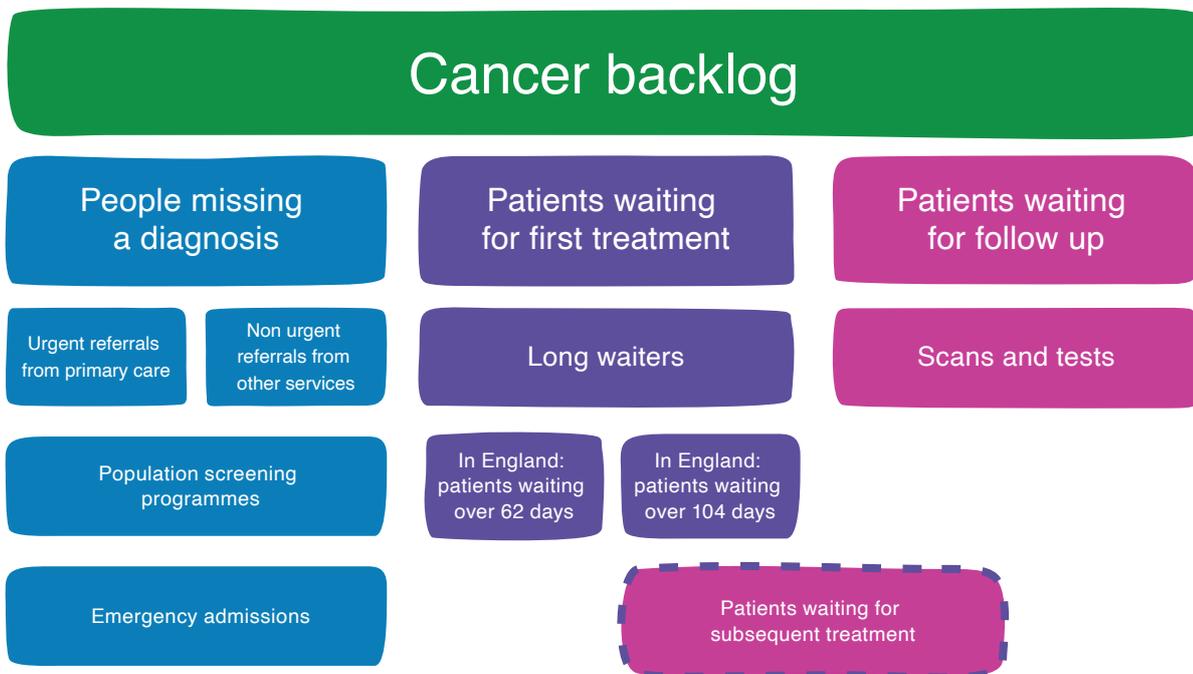
- Included the stories and experience shared with Macmillan’s People and Community Engagement team throughout the pandemic, including through peer support groups and networks and our Telephone Buddying service.
- Spoke with Macmillan campaigners whose treatment was impacted by the pandemic.
- Commissioned a Macmillan Cancer Support/ YouGov survey of 2,202 adults across the UK with a previous cancer diagnosis.<sup>1</sup>

# What is the cancer 'backlog'?

Macmillan defines the cancer backlog as being everyone who is currently missing a cancer diagnosis, test or treatment which we would ordinarily expect them to have.

This is based on the number of people we would have expected to see receive a cancer diagnosis following a referral from their GP or elsewhere to investigate possible symptoms of cancer or those who have received invitations to attend routine breast, bowel or cervical screening, and everyone who is already 'in the system' waiting too long for their first treatment to start or for follow up scans, investigations and treatment for an existing cancer diagnosis.

Essentially – it is the difference between the cancer care activity that has happened in 2020 compared to 2019 levels. We do not have published data for all these strands of activity, but we believe it could impact people across the following areas:



## Key findings

Macmillan estimates that across the UK there are currently around 50,000 'missing diagnoses' – meaning that compared to a similar time frame last year, 50,000 fewer people have been diagnosed with cancer.

**In England urgent referrals** statistics for August show activity is still 11% behind 2019 levels, with each month below pre-pandemic activity levels continuing to add to the backlog. Macmillan's analysis of the trajectory of the rate of recovery suggests it would take **20 months to work through this diagnosis backlog if activity was increased to 10% above pre-pandemic levels and sustained.**<sup>2</sup> This would take 11 months if activity reached and remained at 20% above pre-pandemic levels.

**In England starting 'first treatment'** statistics for August show activity is still 18% behind 2019 levels, with each month below pre-pandemic levels continuing to add to the backlog. Macmillan's analysis of the trajectory of the rate of recovery suggests it would take **17 months to work through this backlog if the number of first treatments increased to 10% above pre-pandemic levels and remained there.**<sup>3</sup> Alternatively it would take 12 months if activity reached 20% above pre-pandemic levels.

Given the current recovery trajectories and worrying indications of the rise in Covid-19 cases across the UK, we consider these to be 'best case' scenarios. We believe if cancer referrals and screening do not return to pre-pandemic levels, the backlog could grow by almost 4,000 missing diagnoses every month, reaching over 100,000 by October next year.

Patients with the most urgent need should be prioritised. However, whilst we have not modelled what these figures mean for mortality, Macmillan fears that for some people their chance of survival will be reduced and that untimely cancer diagnoses could result in significant loss of life. The impact of longer waits for those who are considered less

urgent and able to wait longer for tests or treatment will also cause significant distress and anxiety for many thousands of others.

To better understand the experience of people living with cancer during the Covid-19 pandemic we commissioned a large-scale survey in the summer of 2020. We found that the impact on people's lives and treatment has been significant. The survey is a representative sample of people living with cancer across the UK, which means that:

More than **650,000 people with cancer in the UK (22%) have experienced disruption to their cancer treatment or care** because of Covid-19.<sup>4</sup> This includes many thousands of people who may not be in active treatment but still require follow up care and support following an earlier cancer diagnosis. For around 150,000 people this included delayed, rescheduled or cancelled treatment.<sup>5</sup> Of these, more than half (57%) told us they were worried that delays to their treatment could affect their chance of survival.

Around half (50%) of all those currently having cancer treatment experienced disruption such as **delays, changes or cancellations** including:

- More than one in four (29%) currently having treatment have had at least one test, scan or treatment delayed or rescheduled
- One in 13 (8%) have had to travel to a different hospital than usual for their care
- One in 17 (6%) have had a test, scan or treatment cancelled
- One in six (17%) have had to go for a test, scan or treatment on their own against their wishes.

And a further **90,000 people living with cancer in the UK (3%) had not experienced disruption to their care, but had experienced possible symptoms of their cancer getting worse or coming back and had not yet told their GP or healthcare team** because they're either scared of catching the coronavirus or they do not want to add to the current pressure on the NHS.<sup>6</sup>

# Why did the backlog develop?

At the peak of the pandemic across the UK usual NHS activity faltered. Elective care ground to a halt as millions of operations, clinics and appointments were delayed and cancelled to divert resource to the Covid-19 response.

Screening programmes were paused. Millions of people shied away from making appointments with their GP, or their experience with their GP was disrupted so a referral that might have been made, wasn't.

NHS guidance across the UK was clear that urgent cancer care should continue. However, we know there was a disconnect between these assurances and what happened on the ground.

At the earliest stage some cancer treatment was paused as a precaution because too little was known about the impact a Covid-19 infection could have on people with cancer, particularly for the immunosuppressed. Some procedures, such as endoscopy, suffered significant disruption due to their aerosol-generating nature and risk of infection whilst carrying them out. It took time for guidance to be issued on how to proceed safely and with the least risk.

However, we also know that blanket decisions were made to reallocate staff or resource away from cancer services, for example impacting all major screening programmes and many surgical procedures. At the peak of the pandemic four hundred of Macmillan's own health care professionals were redeployed away from cancer services to the Covid-19 response and we believe many more cancer professionals across the NHS will also have been diverted away from cancer care.

We also know that decisions to pause treatment were meant to be agreed between health professionals and their patients on an individual clinical basis. Macmillan has heard many examples of where this simply was not the case.

Our survey of people living with cancer found that **of those who told us that at least one of their tests or scans had been delayed or rescheduled, more than half (54%) said their healthcare team had made this decision either without their input or against their wishes.** Alongside delays to people already waiting for diagnosis or treatment, there was a catastrophic reduction in urgent referrals from GPs for diagnostic procedures. At the height of lockdown many people stopped going to see their GP, with anxiety about taking up NHS time and fears of the risk of catching Covid-19 outweighing worries about any symptoms of cancer they might be experiencing.

It is vital that confidence in using the NHS is boosted – both for those who are yet to enter healthcare and for those who need to interact with it. Our polling showed that patient confidence in using NHS services for cancer care during the pandemic would be supported if they were reassured that services had put special measures in place to be protected from Covid-19 – 61% of people living with cancer agreed this was the case. 65% agreed that they would feel safer and more confident using the NHS if staff have the right Personal Protective Equipment. The importance of testing was also clear – over half (58%) agreed that they would feel safer and more confident using the NHS if they also know staff are being tested for Covid-19 once a week and a similar number (54%) if they know that all patients are tested for Covid-19 before operations.

The reduction in patients' access to health care – whether via their GP for urgent referral to investigate symptoms, the shutdown of population screening or the large reduction in use of emergency services – has reduced the number of patients being tested and then diagnosed with cancer. The pressures on treatment services as they work in productivity-challenged environments because of new requirements around use of Personal Protective Equipment, additional deep cleaning and social distancing rules mean that many services can't see the volume of patients they may have done before Covid-19. This will contribute to future challenges when the number of people being diagnosed returns to normal (or indeed above normal levels) and creates additional 'pent up demand' in the system.

65% agreed that they would feel safer and more confident using the NHS if staff have the right personal protective equipment. The importance of testing was also clear – over half (58%) agreed that they would feel safer and more confident using the NHS if they also know staff are being tested for Covid-19 once a week.

# Simon's Story

**I was first told I had a brain tumour way back in March 2018. I had two operations in 2018 and thankfully they made me a lot better. I was very fit and active all of last year.**

Then it came to 2020. At the beginning of March I was feeling very unwell and dizzy and was prescribed tablets by my GP. I was anxious but my routine scan was two weeks away so I thought that would pick up if anything is untoward or dodgy. But like everything, it was cancelled. I was worried as I was so sure something was wrong, and made numerous phone calls to the MRI centre and to the Neurology Department but it still took two and a half months to get my scan done, and then only as I'd ranted and complained. I then had a phone call towards the end of May, to tell me 'I'm sorry Mr Green, you were right, the brain tumour has come back, and it's now inoperable'. I was devastated.

I was told any treatment would not be a cure but just suspend the inevitable and give me longer to live, they said I had about two years. Because of the Covid crisis no one could attend the hospital with me, and I had to deal with this news alone, I was speechless.

I felt devastated. Having that sort of news at any time is devastating, but it's the worst when you have to go home, alone, sit in the house and look at four walls and think about how this virus might just continue on, and on, and on.

I had six sessions of chemo, but this made me very ill, so much so they stopped it. When having the chemo I was very weak and just going from bed to sofa, too tired to do anything, even eat and transferring from my wheelchair was hard. I'm happy to say that despite losing weight I am feeling fitter and stronger again and starting radiotherapy this week for six weeks. I am worried, terrified that radiotherapy may make me ill like the chemo did as am normally so active, and it's tough isolating alone when I am ill. I'd already had cancer; it had been cured through surgery. As soon as I'd said I was feeling a bit strange, a bit dizzy, my head didn't feel right, I should have been seen straight away. I should never have had that MRI cancelled. If they'd found it in March and operated straight away, could I have been around in 10, 20 or 40 years' time? I'll never know that.

I intend to live each day to the full, even though it might be harder due to Covid-19.



Simon, diagnosed with cancer aged 42

# The impact of disruption to services on people living with cancer

Delays to cancer diagnosis and treatment can have a profound impact on both the quality of life and, sadly, the clinical outcomes of individuals affected.

For some people, if their cancer is not diagnosed and treated in a timely way it could reduce their chance of survival, especially where their cancer has grown and metastasised during that period. For example, one study relating to lung cancer suggests a 16% increase in mortality if the time from diagnosis to surgery is more than 40 days.<sup>7</sup>

Macmillan's new analysis does not make a prediction about what the disruption to cancer services caused by the pandemic may mean for additional deaths from cancer, however one study published by DATA-CAN and University College London estimated that the pandemic could result in additional 6,270 deaths over the next 12 months in people newly diagnosed with cancer.<sup>8</sup> This number rises to an estimated additional 17,915 additional deaths taking into account all people currently living with cancer.

We have heard from people living with cancer that they are deeply concerned about the progression of their cancer whilst services are disrupted. **One in 11 (9%) of respondents to our survey who had been diagnosed with cancer but not yet started treatment said their cancer had progressed or their symptoms had got worse as a result of the coronavirus disruption.**

Delays in treatment can also exert a significant toll on people's emotional and mental as well as physical health, severely impacting their quality of life. Our survey of people living with cancer found that **people whose treatment has been delayed or cancelled are significantly more likely to be feeling stressed, anxious or depressed** because of Covid-19 than those whose care hadn't been disrupted (41% versus 25%).

# Andrea's story

I've had lots of delays to my care and treatment before Covid happened, but Covid has made these worse. In my surgical consultation, the doctor said he'd be able to reduce the risk of breast cancer by 40% on the other breast, and reduce the size of my breasts so they are more manageable and give me less backpain. So, before the pandemic we'd agreed I would have a therapeutic mammoplasty, rather than a mastectomy. It was the right treatment for me.



Andrea, diagnosed with cancer aged 48

Then just a few days before my operation the breast cancer nurse called me and told me that the hospital had decided that because of coronavirus, only operations deemed lifesaving can go ahead, so my therapeutic mammoplasty wouldn't go forward. I had to have a mastectomy or a wide local excision instead.

I found this really, really challenging. The thing is that you can't have a breast reduction after you've had radiotherapy because it is unlikely to heal properly. Because I couldn't wait until after Covid, it was now or never. I had to state my case strongly a few times, but finally they agreed to do the operation that was right for me. It seems that all choice is gone because of the pandemic.

They told me when I had this operation that in six months they'd balance up the other side. It's now seven months' time. The swelling is getting worse, the pain is getting worse. I think because of Covid restrictions I will still be walking around with mismatched breasts for over a year by the time I get my second operation.

I can't wait for the time I can try and forget about this mess, and get on with a normal life without having the burden of treatment hanging over my life. Covid and Cancer just don't mix.'

‘Because I couldn't wait until after Covid, it was now or never.’

In addition to delayed or cancelled appointments the Covid-19 epidemic has also brought about a significant change in the way many people experience care. For some, changes such as the shift to remote appointments can be positive, with people telling us they like these because they are convenient and make it easy to have a companion present for support. But others have found remote appointments challenging, particularly where they have taken the place of face to face appointments that would normally include a physical check-up:

*'Am I getting better? I haven't been examined for ages. I just don't know if I'm OK. Not having a one to one for reassurance. I'm not having 3 months check-up and so the phone call is not enough.'*

*'I feel like I'm always worrying 'Am I OK or am I being paranoid?' A face to face doctor appointment or blood test would put that worry to rest but isn't really possible.'*

## ● I feel like I'm always worrying 'Am I OK or am I being paranoid?' ●

Whilst recognising that many positive changes may come from services and professionals having the flexibility to adopt creative new ways of meeting patient need in altered circumstances, we must also remain alert to the potential negative impact of rapid innovations and unintended consequences which may reduce access or worsen experience for certain groups. It will therefore be important to carry out impact assessments on the impact of remote appointments on patient outcomes and experience.

Macmillan has also heard that many people living with cancer have also been forced to attend appointments alone, without the vital support of relatives and friends to help them to understand discussions and make decisions.

One person told us:

*'Having to go to appointments on my own... it's horrendous.'*

# Sarah's story

I went the GP last October with a lump and he referred me to the local hospital for blood tests, I then had a mammogram followed by a biopsy and was diagnosed with breast cancer soon after. They started treatment very quickly. I had my first two sets of treatment and then in March we went into lockdown. I'm not going to lie; it was worrying me that I was going to have to keep going into the hospital.

But then I was told the treatment was moving to the 'cancer hub' down the road. Before I went in for treatment I had to go into a tent where they checked my temperature and blood pressure and I had to answer some screening questions, no one was allowed to go into the hospital unless they'd gone through that process. I felt surprisingly safe at the hub with all the safety measures put in place, but my partner was not allowed in – it was hard doing it alone! This happened just as my treatment was moving from monthly to weekly.

I had 12 weeks of chemotherapy. The nurses were great and put everyone at ease. It was difficult to chat with other patients because we were socially distanced, which made it harder to make friends and it did feel quite isolating. But because I went on a set day I still saw the same nurses and the same other patients which was lovely. They were the only people I had interaction with throughout lockdown apart from my partner due to shielding so my weekly sessions became something to look forward to.

I feel very, very lucky my treatment went ahead as planned. My main concern is people thinking that GPs are not seeing people. Everyone needs to be seen. I had a lump last year, I put it off. Had I not been able to see a GP, I may have put it off further and I don't know where I'd be now. People need to know that they can see a doctor if they are worried about cancer. They should go.



Sarah, diagnosed with cancer aged 53

‘The nurses were great and put everyone at ease.’

Sarah's story shows the importance of Covid-protected hubs both in keeping services running and helping people to feel safe and encourage them to attend. However, many people living with cancer have told us that they are still unsure or worried about how safe NHS services are. Some aren't sure what they have to do to comply with Covid-safe procedures before their appointments and treatment and have highlighted that there is a lack of consistency:

*'Why is there such variation on testing people for covid before chemo? Some are doing it before the first treatment, others before every treatment.'*

The pandemic, and periods of lockdown, have brought about challenges and upheavals in everyone's way of life. But having additional worries about what catching Covid-19 might mean for your health or your health care, is an exceptionally difficult situation for many people living with cancer.

We have heard that some people living with cancer felt alone and were left without vital support when changes and delays were made to their treatment:

*'We feel abandoned after my husband's diagnosis two weeks before lockdown – and all through it.'*

*'I felt completely abandoned by the team. My cancer surgery was cancelled in March and I was told patients no longer had any say in their treatment. I had no calls or emails to follow up and show compassion, even if they couldn't treat.'*

Many people living with cancer have told us about their experience of delays to vital follow up tests and scans over the last few months:

**Why is there such variation on testing people for covid before chemo? Some are doing it before the first treatment, others before every treatment.**

**Person with a treatable but not curable cancer.**

# Catherine's story



Catherine, diagnosed with cancer aged 53

**'I had just got to the end of treatment for breast cancer when the lockdown happened. Just before then, my oncologist had agreed to organise a scan for me as I'd been having ongoing health issues, but I didn't even hear anything back and I had to chase a few times before it was eventually booked for June.'**

I found this period very stressful as I was not only coming to terms with shielding following 18 turbulent and lonely months, but also worried about my health and scared that I may have a recurrence. Months waiting and worrying were incredibly challenging on top of everything else.'

Poor communication has compounded the worries of many, who were unclear about who to turn to for support or to ask questions. At the peak of disruption to services early in the pandemic, the NHS insisted that safety netting was in place and that local teams were monitoring patients and aware of their priority status within the system. Unfortunately, even if services were confident in their processes patients were often left in the dark about what this meant for them. Many told us about unacceptably poor communication with health care teams which left them feeling anxious and frightened that their cancer could be progressing whilst they waited for further tests or more information:

*'I'm fed up of having to be so proactive to get care. I should be told my bloods are needed, and asked where I would like them to be done – not to have to ask if they need to be done.'*

*'She was referred to have surgery, was told by specialist that, due to her being on tamoxifen, she would get gold standard treatment with a surgery date in 2–4 weeks of that appointment. 6 weeks on and no contact whatsoever.'*

*'I felt I had to push for stuff, like results and I'm not really that type of person. You feel like people could be forgot about, meanwhile their*

*disease is progressing. People don't know what's happening and go to bed with worry every night.'*

Very sadly, we have also heard from people who believe that delays to follow up scans have resulted in their cancer becoming inoperable:

*'I genuinely feel that if I hadn't ranted and gone on at them, I still wouldn't have had my scan by now. Those months waiting for them to finally agree for me to have a scan would have made all the difference to the outcome for me.'*

For those people facing the end of their lives or an uncertain future, the sense of being abandoned or forgotten has caused a profound anguish, and we have heard heart-breaking stories from people who have experienced a complete loss of hope for the future:

*'Having a terminal diagnosis, the trials had given a glimmer of hope and something to aim towards – this has now been taken away.'*

*'I've asked God to speed it up because I've had enough.'*

One person living with cancer told us simply that they felt they had been 'left on the shelf.'

# Our recommendations to Governments and the NHS across the UK

We have shown above that the coronavirus pandemic has left many thousands of people missing a cancer diagnosis or treatment and inflicted a devastating emotional and physical toll on those whose care has been disrupted.

Across the UK the NHS is working hard to restore all services and local services are doing everything in their power to respond, having been tasked by NHS leaders to recover services to pre-pandemic levels. But the challenge is mammoth. Not only will health systems have to address the pent-up demand from missing patients who have finally received referrals for diagnosis and treatment; they are being asked to do so with additional constraints to capacity caused by infection control measures such as social distancing, use of PPE and additional cleaning. All of this must be done throughout winter – traditionally a time of increased pressure on health services – and in the context of rapidly rising rates of Covid-19. We have heard concerns from people working with or for cancer services that a second wave of Covid-19 could destabilise recovery plans by further reducing referrals, affecting diagnostic capacity and staffing levels.

We need national-level action to protect cancer services and to deliver extra capacity – higher than pre-pandemic levels of activity – to reduce the backlog for people waiting now and to make sure it doesn't continue to grow in the second wave.

Macmillan is clear that the scale of the response must meet the scale of the challenge. We are calling for governments and NHS leaders across the UK to prove this won't happen again and to promise that cancer will not become the forgotten 'C' of the Covid-19 pandemic by taking the following actions:

**Governments must prevent the cancer backlog from increasing by committing to ring-fence cancer services to protect them from the impact of a second wave of Covid-19.**

- We must learn lessons from the first wave and commitments to prioritise essential cancer services from disruption must be met, with stronger mandatory guidance put in place.
- Changes to treatment should only ever be made on an individual basis and discussed with the individual. There should never be blanket service suspensions.

**The NHS should protect cancer services by ringfencing the capacity needed to keep Covid-protected services running, with no redeployment of staffing or repurposing of resource (this includes protecting the real estate space, beds, equipment and transport needed to maintain services).**

**Further measures must include:**

- Standardised testing regimes across all providers offering rapid turnaround testing for patients and frequent, rapid turnaround asymptomatic testing of staff. There should be national standards and guidance in place on testing protocols to avoid unacceptable variation in practice. Where Covid-19 infection control measures include patient testing prior to an intervention, this should follow best-practice guidance that also takes into account a patient's circumstances.
- The right Personal Protective Equipment for staff across all settings including primary and social care.
- Ongoing access to independent sector estate space and workforce capacity for as long as required to guarantee services can be delivered in Covid-protected spaces.
- National service specifications for cancer services setting out the appropriate sustainable Covid-19 infection control measures which should be in place.
- Guaranteed resources for additional costs resulting from new ways of working including staffing, transport, procurement of equipment and/or refitting of facilities to allow for infection control or social distancing measures.

**Governments should commit to providing the additional resource required to increase capacity and reduce the cancer service backlog as soon as possible. NHS activity levels have to rise above pre-pandemic levels in order to catch up on missed diagnosis and care. To support this:**

- Ongoing provision of additional resource may be needed, for example continued use of independent sector resource for interventions such as surgery or endoscopy, staffing overtime or new equipment.
- This may also require repurposing of other capacity – such as through specific facilities (like the Nightingale Hospitals) – or through waiting list initiatives.
- National service specifications will help services to respond flexibly across usual provider boundaries if required.
- For anyone whose treatment continues to be affected, there must be a clear plan to return to these individuals as soon as possible, and in the meantime, they should be offered a package of clinical, emotional and practical support to meet their needs.

**It is critical that the number of people seeing their GP with suspected cancer symptoms returns to normal levels. To support this there must be a sustained public awareness and information campaign to encourage symptom awareness and provide reassurance to people who are still anxious about accessing primary care and other services that it is safe to do so. This should include sustained and tailored messaging on lung cancer symptoms.**

**Governments should urgently commit to the long-term investment needed to create a sustainable cancer workforce. The strain placed on the entire health care ecosystem by the Covid-19 pandemic whilst understandable at some level, highlights long term systemic challenges for the cancer and wider NHS workforce. The redeployment of staff and long decline in cancer waiting times performance standards across the UK demonstrates the fragility of services, even before Covid-19. In the short-term plans to both support and make best use of the available workforce must be developed:**

- Many staff may have experienced significant physical and emotional challenges working through the peak of the Covid-19 outbreak and it is imperative that there is enhanced support in place to support staff at risk of burnout.
- Many lessons can be learnt from the pragmatic, flexible and collaborative approach to staffing and service delivery which was adopted by healthcare professionals across the NHS during the peak of Covid-19. This includes the movement of health care professionals between NHS Trusts and health boards and deploying staff with more varied skills, both of which should be adopted to approach the backlog in cancer patients, where the capacity in the existing cancer workforce is unlikely to be sufficient.
- The NHS should take the opportunity to reconsider the importance of best use of skill mix across multidisciplinary teams, for example by building on new ways of working that demonstrate that Band 4 workers were able to perform a number of roles they hadn't previously.

**There should be ongoing and timely publication of data showing the scale of the backlog caused at local and national level as well as progress in recovering services:**

- This should include the number of diagnoses that have not been made as expected in 2020 via any route, as well as tests and treatment for patients with an existing cancer diagnosis.
- Data should be disaggregated by demographic characteristics in order to monitor the impact on vulnerable groups and take targeted action if necessary.

**The NHS should confirm the existing commitments 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 recovery 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.**

- All people diagnosed with cancer or experiencing changes to their treatment and support should have access to a Holistic Needs Assessment (HNA) or Electronic Holistic Needs Assessment (eHNA) and a care plan and the health and wellbeing information and support necessary to meet their needs.
- The use of digital services during the Covid-19 crisis, particularly in primary care, also offers an enhanced opportunity to deliver personalised care. This approach has allowed people to complete holistic needs assessments online and send back without having to see a clinician. However, it is important to recognise that digital platforms should be a patient choice and should not exclude access to healthcare for those who are less able or who prefer not to navigate online support.

Health services need to provide **much better communication with patients**, communicating with individuals directly to explicitly address any concerns over the safety of treatment, to build confidence in the system and to ensure that people are involved in decisions about their care and have the support they need.

It is vital that the government ensures that **that no person living with cancer is left behind and that health inequalities do not widen as a result of the Covid-19 pandemic.**

- Permanent changes in ways of working such as the shift to remote appointments or 'call before you walk' initiatives in urgent care settings must not exacerbate existing inequalities in people's access to or experience of care.
- Impact analysis should be carried out to ensure that nobody is left behind.

In the next section, we have provided our analysis of the cancer backlog in each nation of the UK. As health care is devolved, and therefore data capture and publication differs, we have conducted four separate analyses for each part of the UK. It is important to note that it is not possible to make comparisons between nations and we have not sought to do this.

# THE FORGOTTEN 'C': ENGLAND

## Key findings

Macmillan estimates that there are currently around **42,000** 'missing' diagnoses in England.

Furthermore, the scale of this backlog is so significant that it would take substantial additional capacity and for the NHS to operate at higher levels of activity than before the pandemic in order to catch up.

**Urgent referrals:** Statistics for August show activity still 11% behind 2019 levels, with each month below pre-pandemic activity levels continuing to add to the backlog.

Macmillan's analysis of the trajectory of the rate of recovery suggests it would take **20 months to work through this diagnosis backlog if activity was increased to 10% above pre-pandemic levels** and sustained.<sup>9</sup> Recovery would take 11 months if activity reached and remained at 20% above pre-pandemic levels.

**Starting first treatment:** Statistics for August show activity still 18% behind 2019 levels, with each month below pre-pandemic levels continuing to add to the backlog.

Macmillan's analysis of the trajectory of the rate of recovery suggests it would **take 17 months to work through this backlog if the number of first treatments increased to 10% above pre-pandemic levels** and remained there.<sup>10</sup>

Recovery would take 12 months if activity reached 20% above pre-pandemic levels.



## What happened to cancer services during the peak of the pandemic?

In a letter sent to NHS England leaders and providers in March 2020,<sup>11</sup> Sir Simon Stevens set out plans for the urgent response to the Covid-19 pandemic and explicitly stated that ‘emergency admissions, cancer treatment and other clinically urgent care should continue unaffected’.

Subsequent clinical specialty guidance set out the approach that clinicians in the NHS in England were asked to take when treating cancer patients during the period of system pressure.<sup>12</sup> This was reinforced by a letter confirming that delivering urgent and essential cancer care must continue to be a priority.<sup>13</sup> Defining ‘urgent and essential’ cancer care is informed by clinical guidance and uses criteria for surgery, chemotherapy and radiotherapy that takes into account the individual nature of someone’s cancer (i.e. how fast it might grow and the potential benefits of the treatment). However, we know that at the peak of the pandemic there was significant disruption to cancer treatment in England, not all based on individual clinical decision making. For example, in early March, University Hospitals Birmingham Trust confirmed it had cancelled some treatments, including chemotherapy, stating ‘in view of the pressures posed by coronavirus, the trust is having to make some difficult decisions to allow our staff and resources to be deployed effectively to cope with the current and anticipated pressures’.<sup>14</sup> On 1st April it was confirmed that the Trust had written to patients to confirm suspension of non-urgent surgery, including non-urgent cancer surgery.<sup>15</sup>

Throughout the last six months Macmillan has been aware of anecdotal and other evidence confirming that dozens of hospital trusts changed the delivery of cancer care. Some of these changes may have been appropriate – for example relocation to safer environments or those based on an individual’s circumstances – but we know that this was not always the case and some changes were made in order to redirect resource towards the Covid-19 response. We also know that there were unofficial pauses to screening programmes.

As Covid-19 cases eased and the health system became more used to dealing with its impact, in July 2020 the NHS in England moved into the third, ‘restoration’ phase of the Covid-19 response. In a letter,<sup>16</sup> Sir Simon Stevens asked systems to plan for the restoration of cancer services to pre-Covid levels between September 2020 and March 2021. Systems were asked to put plans in place for those who have experienced long waits (over 104 days) as a result of Covid-19 disruptions as well as to manage the immediate growth in people requiring cancer diagnosis and/or treatment by ensuring sufficient diagnostic capacity is in place in Covid-19 secure environments; increasing endoscopy capacity to normal levels; and expanding the capacity of surgical hubs.

Macmillan welcomes the many innovations and adaptations that have taken place to deliver safe care – innovations such as the establishment of Covid-19 protected hubs, increased use of mobile buses for chemotherapy and rapid approval of new treatment modes. But it is important that these are supported to continue for the medium-term. The NHS was promised ‘whatever it needed’ to deal with the impact of Covid-19, and it is vital that funding does not cease now, when the challenge for cancer is still unfolding. Macmillan has heard, for example, that mobile chemotherapy units which have been very helpful in moving services outside hospitals, providing flexibility and reassurance to patients who are anxious about going into large healthcare settings, have to be shared between services. We need more of this resource if we are to protect cancer services throughout winter and a second wave of Covid-19.

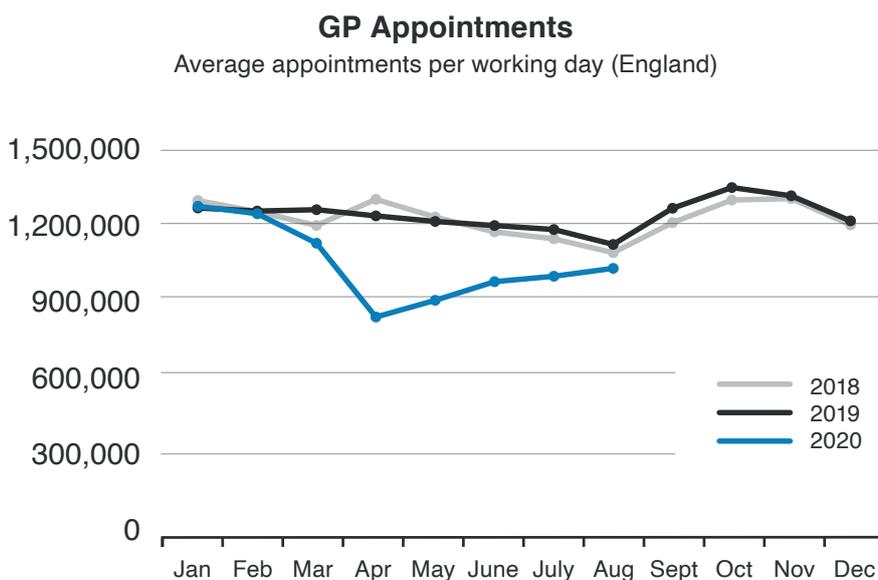
## The impact of the first wave on cancer care

However, we know that the impact on patients in England has been significant, with substantial drops in the numbers of people being referred for investigations into cancer symptoms and the numbers of people undergoing treatment.

At the peak of the first wave of the pandemic the number of people having appointments with their GP with concerns about symptoms fell dramatically compared to previous years. The graph below demonstrates the scale of the drop (note these are not cancer specific appointments).

This in turn led to a catastrophic reduction in the number of people being referred by a GP to a specialist on the urgent referral pathway. Macmillan analysis shows that over the six months since the start of the pandemic, there has been a 28% decrease in urgent referral appointments taking place in England for people with suspected cancer<sup>17</sup> – meaning there have been 343,000 fewer patients with symptoms being tested for suspected cancer.

The Health and Social Care Committee inquiry into Delivering core NHS and care services during the pandemic and beyond<sup>18</sup> heard from the NHS England Clinical Director for Cancer, Dame Cally Palmer that on 1 May 2020 chemotherapy appointments were ‘running at about 70% of normal levels’, and the Royal College of Pathologists reported that 6,000 fewer people than expected had received chemotherapy since the start of lockdown.



## October 2020: have cancer services been restored?

Over the summer of 2020 Cancer Waiting Times data demonstrated the impact of the drop in urgent referrals, with statistics showing that thousands fewer patients were starting treatment than we would normally expect.

It is now very clear that many thousands of people who should have a cancer diagnosis have not received one. We are also concerned that the reduction in referrals and reduced productivity in diagnostic procedures such as endoscopies and scans has artificially reduced the volume of people requiring treatment, and that these services may begin to buckle under pressure in future.

In order to catch up with the backlog that has developed, cancer services have to increase the volume of patients that are being diagnosed and starting treatment for cancer. This means we need all the people with health concerns who have until now been too worried to see their GP to make an appointment. Screening programmes need to invite people to take part. It also means that diagnostic services will have to urgently ramp up capacity to reduce the existing bottleneck and treatment services will have to prepare for an increased number of patients as pent up demand moves through the system.

The impact of a second wave of Covid-19 poses substantial risk to the recovery of cancer services. There have already been reports of trusts making changes to cancer services and redeploying staff in preparation for an escalation of their Covid-19 response. In Liverpool, Liverpool University Hospitals Foundation has signalled not only that they must now curtail elective activity but – alarmingly – that cancer care is not guaranteed, stating, ‘we will continue to prioritise surgery based on clinical need with a view to maintaining urgent and cancer surgery where possible.’<sup>19</sup> We have heard that there are concerns that a second wave of Covid-19 could de-stabilise recovery plans by reducing referrals further, affecting diagnostic and treatment capacity and redeployment of staff. There are fears that lessons to avoid this impact have not been fully learnt.

Below we assess a number of key metrics to determine the progress made towards restoring diagnostic and treatment capacity.

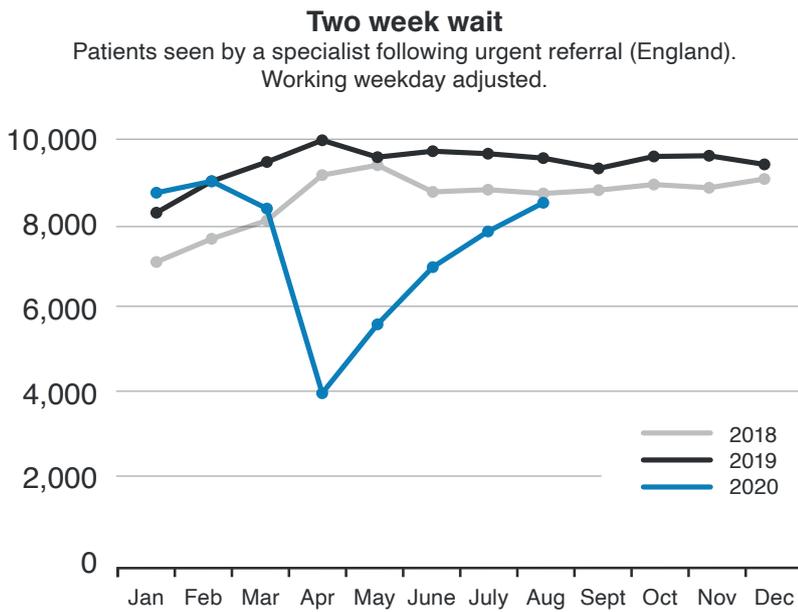
### Urgent referrals

Whilst urgent referrals have climbed back up from the low point in April (when activity dropped by 60% compared to the previous year), they have still not fully recovered. Latest data shows that the number of people in England being seen by a specialist for suspected cancer following an urgent referral by their GP was 169,660 in August 2020. This is **around 30,700 lower** than it was the same time last year<sup>20</sup> – a drop of 11%, adjusting for working weekdays in the month.

The cumulative reduction in referrals between March and August 2020 amounts to 343,000 fewer people seeing a specialist – a 28% drop overall.

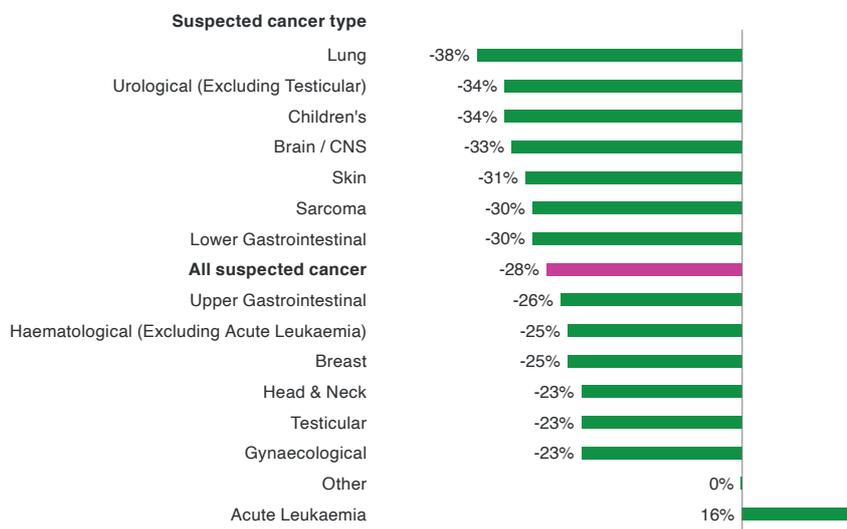
Under normal circumstances around 7% of people who are seen by a specialist for suspected cancer following an urgent GP referral (also known as the ‘two-week-wait’ route) will go on to be diagnosed with cancer.<sup>21</sup> The drop in the number of people being seen via the two-week-wait route in August 2020 could therefore lead to more than 2,000 fewer people having their cancer diagnosed via this route in England.

In addition, only 87.8% of those who saw a specialist did so within two weeks of their initial urgent referral – this is the worst result on record in England for this cancer waiting times target, showing that even where referral levels have reduced, the system is struggling to meet service standards.



Source: Monthly Provider-based Cancer Waiting Times July 2020 (NHS Digital)  
Patients seen by a specialist following urgent referral for suspected cancer.

**Year-on-year % difference in two-week wait appointments  
(March to August 2020 vs 2019)**



## Cancer type variation

Differences are also emerging in relation to urgent referral performance for different tumour types. Appointments for suspected lung cancer suffered a substantial decline and have still not increased in line with some other cancer types, with referrals falling by 38% between March and August and remaining 30% down in August. This is likely to be because of the similarities in symptoms with Covid-19 – primarily coughing – and demonstrates the importance of targeted information campaigns to tackle this problem and ensure people with suspected lung cancer are referred on for further investigations. We are encouraged that a future phase of the ‘Help Us, Help You’ campaign will address lung cancer symptoms specifically.

Urology referrals are also low, with falls of 34% overall between March and August and levels continuing to be at 22% below 2019 levels by August.

## Screening

Many people are diagnosed with cancer following routine screening appointments for breast, bowel and cervical cancer.

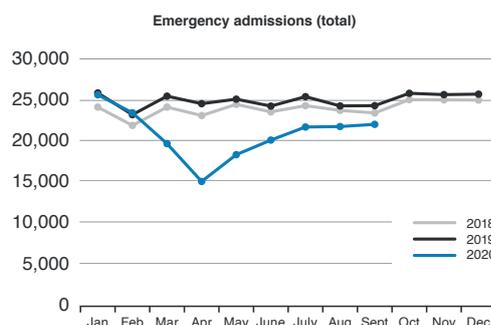
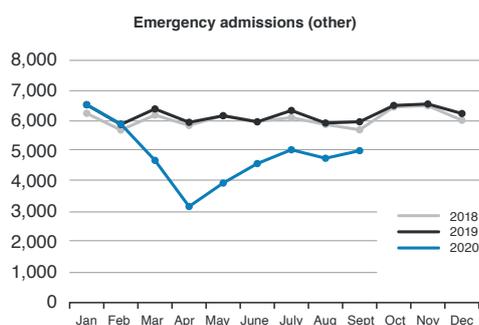
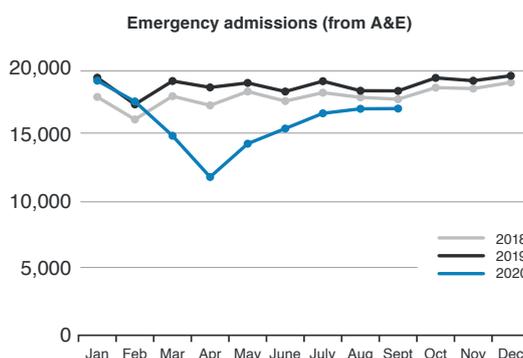
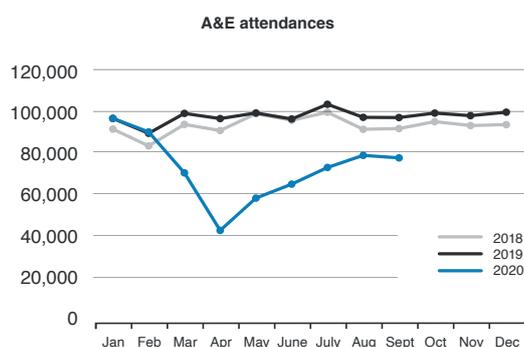
Screening programmes were paused unofficially across England and there is no precise date at which services ceased, as this was locally determined. To determine the likely number of diagnoses missed because of disruption to screening we have made some assumptions about the level of activity carried out between March and August – assuming that there was no activity at all between March and June 2020; and a capacity of up to 25% for July and up to 50% for August when limited invitations began to be sent out again, targeting groups deemed to be of greatest priority.

It is clear that because of the unofficial pausing of screening programmes, there are significantly fewer people being diagnosed with cancer via this route. Our estimation is that there were **around 7,000 fewer diagnoses in the six month period from March 2020.**

We know from official data that in August, the number of people in England starting treatment for cancer following a cancer screening appointment was just 315 – a drop of 81% compared with last year, adjusting for working weekdays in the month. Only just over half of these people (56%) started treatment within 62 days of their screening appointment, against a target of 90%.

### A&E Attendances and emergency admissions

Number of attendances/admissions per working day (England)



## Emergency admissions

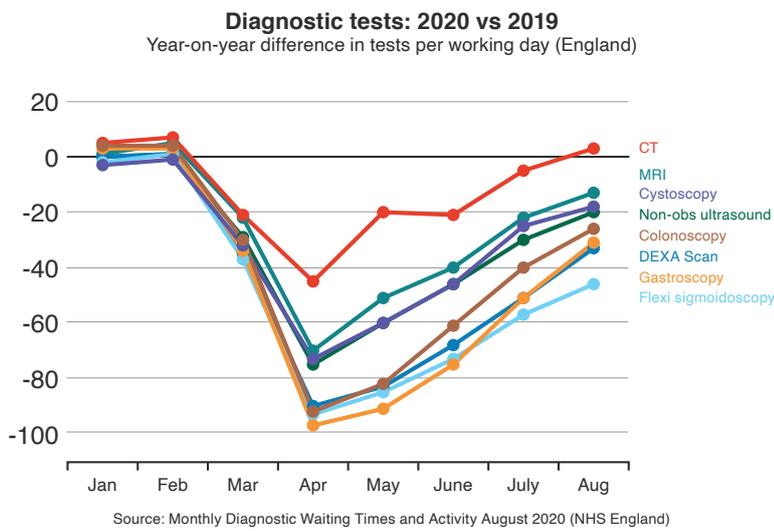
Sadly, some people are diagnosed with cancer only when they present with very acute symptoms at urgent care settings such as Accident and Emergency (A&E) departments. We do not have published statistics to show the impact that reduced attendance at A&E has had on cancer diagnosis. However, we do know that the overall number of people visiting A&E has fallen and we can make estimates of the impact this may have on the number of people being diagnosed with cancer based on the usual number of people we would expect to see being diagnosed by this route.

Emergency admissions were 22% below 2019 levels between March and August and still remain below normal levels. Latest data for September shows there were 479,800 emergency admissions for all causes (not just cancer), which is a 12% drop on the monthly average for 2019.<sup>22</sup> Under normal circumstances, we would expect around 1 in 5 (19%) cancer diagnoses in England to take place following an emergency presentation,<sup>23</sup> and recent trends in diagnoses in England via emergency routes suggest we would have expected around 55,000 cancer diagnoses in 2020.<sup>24</sup> Therefore we estimate this means 6,000 fewer cancer diagnoses between March and August.

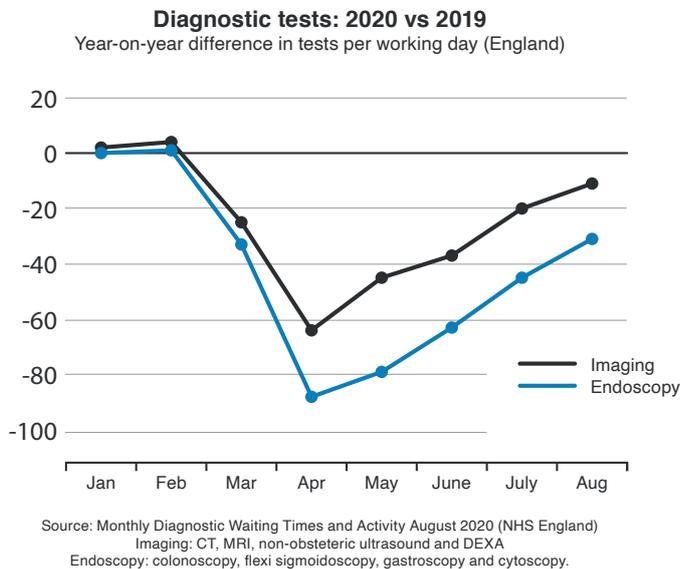
## Diagnostic tests

Once people have received a referral to investigate for possible cancer, they will need to undergo diagnostic tests and scans. The pandemic has magnified the intense pressure that diagnostic services were already under.

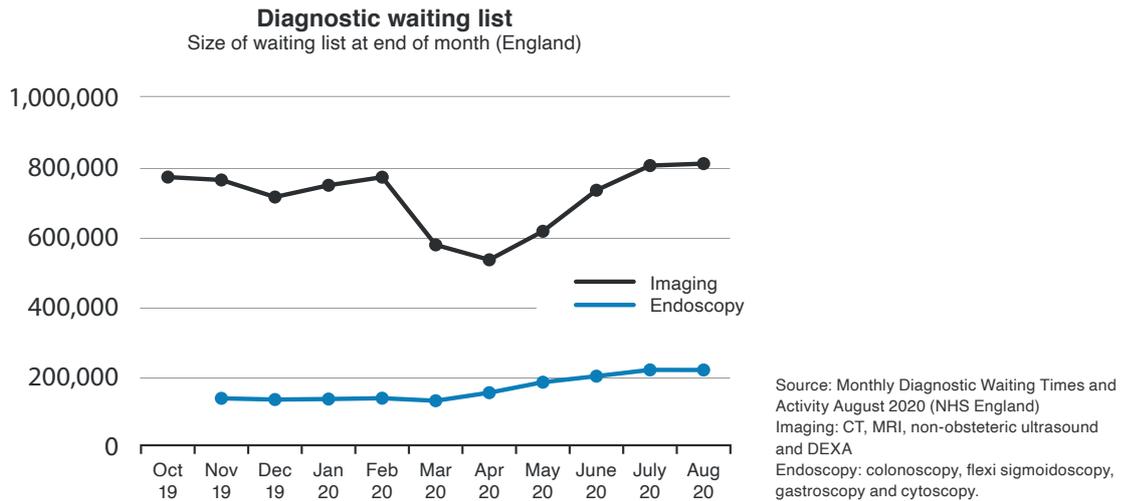
The chart below shows the impact on eight key diagnostic tests (these are not cancer specific, but many people will have to undergo these tests in order to receive a cancer diagnosis).



Endoscopy procedures were significantly impacted early in the pandemic, as were, to a lesser extent, imaging services:



We know that the waiting lists for endoscopies and imaging – key diagnostic tests for cancer – ballooned between March and July 2020, with the waiting list for endoscopies growing by 69% and the waiting list for imaging procedures growing by 41%. Addressing the bottlenecks in diagnostic capacity will be key to tackling the growing backlog.

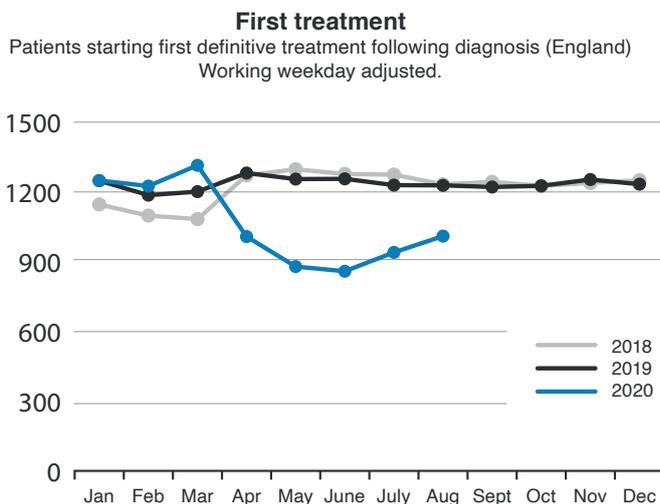


## Cancer treatment

Latest Cancer Waiting Times data also shows that there are still significantly fewer people starting treatment than we would normally expect. Because we know there was an early drop in referrals and diagnosis, we need to see more people starting treatment in order to address the backlog, not fewer.

The number of people starting first treatment in England was still 18% behind 2019 levels in August, adjusting for working weekdays in the month. **Each month at this level amounts to the backlog growing by about 4,500.**

In total, between March and August around 30,000 fewer people started their first cancer treatment, a drop of 19% overall compared to 2019.



Macmillan estimates that the **backlog in treatment would take 17 months to clear if recovery continued to rise until it was 10% above pre-pandemic levels**; and it would take 12 months to clear if it instead increased to and remained at 20% above pre-pandemic levels.

The number of people having surgery as a subsequent treatment for cancer was around 4,000 in August 2020. This is lower than last month's figures and a 4% drop from what we would have expected for August 2020.<sup>25</sup>

The number of people in England starting treatment for cancer following urgent GP referral for suspected cancer specifically (i.e. excluding those diagnosed through other routes, e.g. cancer screening) was 11,197 in August 2020. Under normal circumstances we would have expected this figure to be around 13,700, which means the number of people starting treatment following an urgent GP referral for suspected cancer is **around 2,500 lower** than we would have expected for August 2020<sup>26</sup> – a drop of 14%, adjusting for working weekdays in the month.<sup>27</sup>

## Variation by cancer type

As noted above, the impact of Covid-19 and the lockdown has not been uniform across cancer types. For example, the numbers of people being referred for suspected lung cancer have been slowest to start their recovery – this is particularly concerning given the poor survival rates for this cancer overall and the UK's poor outcomes compared to other countries. However, the number of people starting treatment for lung cancer is showing a lower level of disruption than for many other cancer types.

The number of people starting treatment for breast cancer has seen a significant drop, with around a hundred fewer women starting treatment than expected each working day in May and June 2020. We have also seen lower recovery rates for people starting treatment for urological cancers, such as prostate cancer.

## Further Recommendations

In addition to the recommendations we have already set out for action by UK governments and NHS services across the UK, NHS services in England should also:

- Guarantee full use of independent sector capacity for as long as is needed. Macmillan is concerned by reports from colleagues working in cancer services that for some there is a lack of clarity about what capacity is available and how it should be used by Cancer Alliances and local health economies to prioritise greatest need.
- Urgently prioritise recovery of diagnosis and treatment services for those cancers which have been most impacted and slowest to show recovery.
- Identify regional variation and provide additional support and capacity to those Cancer Alliances
- Rapidly adopt best practice and innovative service models such as mobile chemotherapy buses wherever they are needed
- Provide a comprehensive plan to assess the impact of Covid-19 on health inequalities and take the action necessary to address this.

# THE FORGOTTEN 'C': WALES

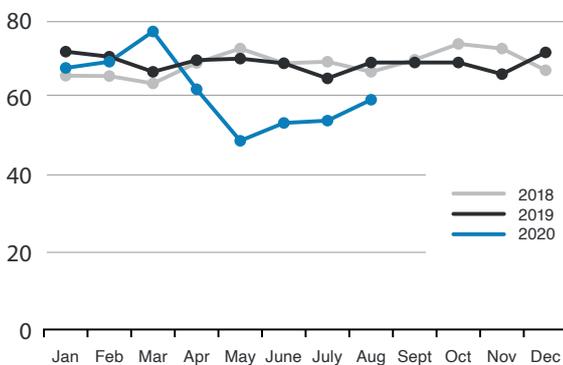
## Key findings

### The diagnostic backlog

Data on the Single Cancer Pathway shows that between March and August of this year **24,000 (31%) fewer patients than usual entered the pathway for a suspected cancer.**<sup>28</sup> Macmillan estimates that there is a backlog of **2,900 fewer diagnoses** from that time period.

This backlog in diagnostics would take 37 months to clear if recovery continued to rise at the latest observed level of improvement until it was at 10% above pre-pandemic levels, and 28 months to clear if it rose substantially to 20% above pre-pandemic levels and remained there.

**First treatments in Wales**  
People per working weekday



### The treatment backlog

Published data shows us that between March and August this year, **1,100 fewer people started their first cancer treatment in Wales** than in the previous year. The number of people starting their first treatment in Wales was still 14% behind 2019 levels in August of this year, adjusting for working weekdays in the month, with each month at this level amounting to the backlog growing by around 200 people.

This backlog in treatment would take 17 months to clear if recovery continued to rise until it was 10% above pre-pandemic levels, and 13 months to clear if it rose substantially to 20% above pre-pandemic levels and remained there



## What happened to cancer services during the peak of the pandemic?

At the start of the Covid-19 pandemic, the Minister for Health and Social Services, Vaughan Gething MS, announced the suspension of non-urgent appointments, treatment and surgery in order to ensure capacity for patients with coronavirus.

He stressed that access to cancer and other essential treatments would continue. This was followed in April by a letter from Dr Andrew Goodall, the Chief Executive of NHS Wales, to all NHS health board chief executives setting out the importance of maintaining cancer services during Covid-19 and asking health boards to ensure the continuation of emergency and urgent cancer care and treatment.

Many non-urgent appointments were changed to remote appointments, and many non-urgent appointments, surgeries and treatments were delayed to ensure there was capacity for Covid-19 patients. While cancer services were maintained, there was significant disruption as health boards adapted to ensure patient safety. These changes meant that individuals had very different experiences through their diagnosis and treatment of cancer. Broadly, health boards were able to maintain chemotherapy and radiotherapy where it was safe to do so, but some complex cancer surgery has faced disruption in parts of Wales.<sup>29, 30, 31</sup>

Endoscopy services were particularly badly affected: the Minister for Health and Social Services outlined in September that the number of people waiting for a diagnostic endoscopy had increased from 11,900 in March to around 15,700 at the end of July.<sup>32</sup> Since then, the Welsh Government has outlined plans to roll out community-based endoscopy centres in town centre locations in order to tackle the backlog.<sup>33</sup>

In May, the Welsh Government published a framework for operating NHS services during the pandemic, as well as guidance on maintaining cancer treatment.<sup>34</sup> The framework aimed to balance reducing the harm from the Covid-19 infection with reducing the harm caused by reduction in non-Covid activity. It outlined guidance on the delivery of essential cancer services that asked health boards to clearly separate Covid and non-Covid patients with dedicated sites, make use of independent sector and field hospital capacity, and to ensure adequate physical and workforce capacity and social distancing and infection control measures. June also saw the Welsh Government launch a communications campaign, supported by Macmillan and the Wales Cancer Alliance, to encourage people with symptoms to come forward.

## The impact of the first wave on cancer care

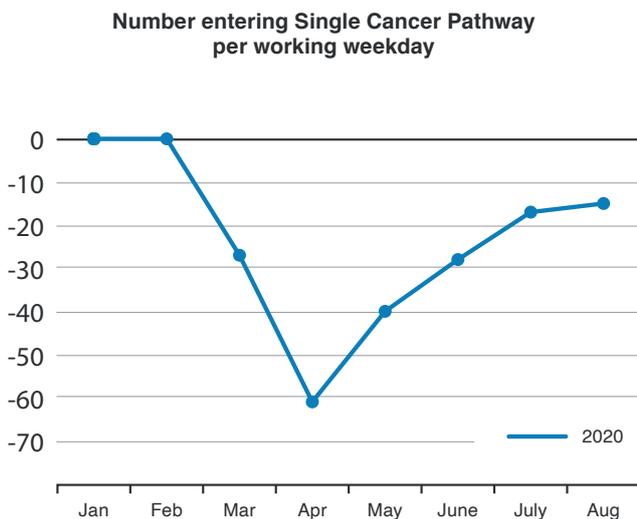
During the initial peak of the pandemic, there was a significant impact on the diagnosis of cancer in Wales. Data from the Single Cancer Pathway showed that in March, patients entering the pathway fell to around 10,000 from a pre-pandemic average of 13,200 per month, and then again dramatically to just over 4,900 in April. This amounts to a 61% drop in the number of referrals compared to the monthly pre-pandemic average. May saw a slight recovery of 7,000 people entering the Single Cancer Pathway, but this remained well below normal levels.

### Referrals for suspected cancer

The Single Cancer Pathway provides an aggregate number of all the main routes to diagnosis for suspected cancers in Wales. It was introduced in 2019 and currently exists alongside historic cancer waiting times figures on referrals that count urgent and non-urgent referrals respectively.

As outlined above, at the peak of the first wave of the pandemic, the number of patients entering the Single Cancer Pathway fell to only 4,913 in April, equating to over 61% fewer referrals than an average month.

The most recent data for the Single Cancer Pathway shows that referrals began to rise again from the lowest point in April, up to 7,055 in May, 9,912 in June, 11,903 in July and 10,555 in August. However, the number of patients entering the pathway in August was still only up to approximately 85% of an average month.



The incredibly low levels of referrals in Wales during the peak of the pandemic mean that between March and July there were **34% fewer patients** than usual referred for diagnostic tests and screening to see whether they have cancer. Using this percentage, Macmillan has estimated a backlog of approximately 2,600 missing diagnoses in the system. If extrapolated to cover the month of August, this figure could rise to **3,200 missing diagnoses**.

This means that diagnostic services in Wales will need to get through a **backlog of around 24,000 patients with suspected cancer** who have not yet come forward with symptoms through the usual channels.

This **backlog in diagnostics would take 37 months to clear** if recovery continued to rise until it was at 10% of pre-pandemic levels, and still 28 months to clear if it remained at 20% above pre-pandemic levels.

Increasing diagnostic capacity to over 100% of what it was pre-pandemic will be essential in order to avoid a significant bottleneck at the front end of the cancer pathway. Any bottleneck in diagnostics will have a serious impact on the ability of those newly diagnosed with cancer to access timely treatment – even if capacity for cancer treatments has improved by that point.

## Diagnosis through screening programmes

On the recommendation of Public Health Wales, the Welsh Government temporarily paused screening programmes for breast, bowel and cervical screening towards the end of March. Public Health Wales recognised that the restart of screening programmes was dependent on the diagnostic and therapeutic capacity of health boards and in May was asked to prepare an assessment for the Welsh Government on the restart of screening services.

In 2018/19, Public Health Wales screened a combined total of 434,671 people across its three screening programmes for cancer. This included 100,472 people attending a breast screening, 160,652 people taking up bowel screening and 173,547 people attending cervical screening.

We know that screening for all three programmes in Wales was paused for at least three full months from the start of April until the end of June, when cervical screening was re-started.<sup>35</sup> Breast and bowel screening began to restart shortly after this.

If we only take into account the three months in which we can be certain there was absolutely no screening taking place (April – June 2020), then we can assume that there was a minimum of approximately **108,700 fewer people participating in screening tests** in Wales than there was over any three-month period in 2018/19.<sup>36</sup> This equates to a backlog of approximately 25,100 people for breast screening, 40,200 people for bowel screening and 43,400 people for cervical screening for the system to manage. As screening programmes were unlikely to have restarted at 100% capacity from the end of June, the backlog of those waiting for screening in Wales is likely to be considerably higher than this base level figure.

Although it is not possible to accurately translate the number of missed screening appointments to the backlog in diagnoses, it is clear that this will have an impact. Reports show that 23% of patients diagnosed with bowel cancer in 2018 were referred via screening programmes in England and Wales, and that 36% of people diagnosed with cervical cancer in 2018–19 were classified as screen detected in Wales.<sup>37</sup> For cervical cancer, it is also clear that the majority of screen detected cancers were at early stage, whereas non-screen detected cancers were mainly at later stage.<sup>38</sup> Over 1,000 cancers were detected by the breast cancer screening programme in Wales in 2017/18.<sup>39</sup> This is a significant backlog in the number of people each screening programme needs to see to try to make up lost ground during the pausing of the programme, as well as needing to continue to provide screening appointments for those who are due appointments over the coming months.

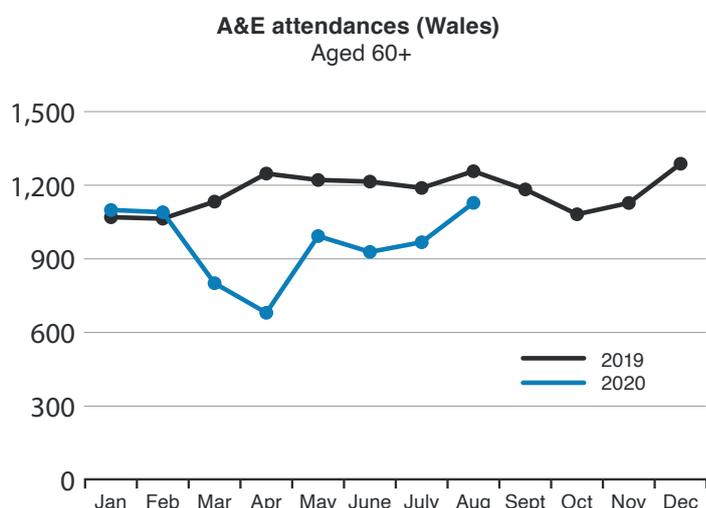
Although all screening has now resumed, there is a significant backlog which will be slower than usual to clear because Covid-secure measures mean fewer people can be seen at each clinic. There has also been an increase in people not attending due to individuals being concerned about the risk of contracting Covid-19.

Public Health Wales has not been able to predict when or if screening services might clear the backlog. Those above the upper age range for breast screening will not be able to self-refer for at least the next six months, and managing attendance in areas of local lockdown has presented a further challenge.

### Emergency admissions

In Wales, as in the other nations, we do not have published data on the impact that reduced attendance at A&E has had on cancer diagnoses. However, we know that the overall number of people visiting A&E fell during the pandemic.

Analysis from the Health Foundation shows that younger people were responsible for a large number of the drop off in A&E attendances earlier in the pandemic.<sup>40</sup> With the data available in Wales, we can ascertain that the older population are most likely to present at an A&E with an undiagnosed cancer. Data shows that A&E attendances for the group aged 60+ were still much lower than they were in 2019 when their age group was isolated, confirming that cancer diagnoses through A&E is likely to have followed a similar trend as other presentation routes and fallen roughly in line with A&E attendance more widely.



Source: Number of attendances in NHS Wales accident and emergency departments by age band, sex and site (StatWales)

## October 2020: have cancer services been restored?

In Wales, the publication of performance statistics for cancer waiting times was paused during the pandemic. This includes data on the Single Cancer Pathway, though publication is expected to resume before the end of 2020.

So, although we can see data on the volume of individuals entering the pathway and starting treatment, we cannot see how Wales is managing against its 62-day standard for patients starting treatment. However, it is likely that, the reduction in referrals and slow-down in diagnostic procedures may have artificially reduced the number of people waiting for treatment who are already within the system. It is therefore important that when considering any data on waiting times for patients already in the system, health boards in Wales fully consider the backlog in diagnostics and treatment as numbers of referrals continue to increase. In July, Dr Goodall told the Welsh Parliament's Health, Social Care and Sport Committee that he expected wider NHS waiting times to take "two or three years as a minimum" to recover.<sup>41</sup>

In order to catch up with the backlog that has developed, cancer services have to increase the volume of patients that are being diagnosed and starting treatment for cancer. This means we need all the people with health concerns who have until now been too worried to see their GP to make an appointment. It also means that diagnostic services will have to urgently ramp up capacity to reduce the existing bottleneck and treatment services will have to prepare for an increased number of patients as pent up demand moves through the system.

### Recommendations:

- The Welsh Government must commit to prioritising and ringfencing cancer services during the second wave of the pandemic.
- The Welsh Government should commit to providing the additional resource required to increase capacity and reduce the cancer backlog as soon as possible, with a clear plan and resources to support the delivery of surge capacity. Where cancer services face disruption locally, local health boards should ensure that patients can still access treatment through regional collaboration with other health boards and use of the independent sector.
- The Welsh Government should develop a targeted, sustained information and communication campaign to improve the rate of suspected cancer referrals and prevent a surge in late-stage diagnoses.
- The Welsh Government should review its suspension of performance reporting against cancer waiting time targets and should consider publishing regular and detailed information on the scale of the cancer backlog. This should include the projected number of missing diagnoses by health board.
- Local health boards should take steps to ensure the principles of personalised cancer care are not forgotten during the pandemic. The role of holistic needs assessments in identifying physical, emotional and practical support needs is just as important now as it has ever been.

# THE FORGOTTEN 'C': NORTHERN IRELAND

## Key findings

### The diagnostic backlog

Macmillan estimates that there were 1,000 fewer cancer diagnoses in Northern Ireland between March and July 2020, creating a significant backlog of patients who are not yet in the system but need to be.

### The treatment backlog

The number of people starting first treatment in Northern Ireland was at 20% behind 2019 levels in June, with a backlog of 200 fewer people starting their first cancer treatment.

## What happened to cancer services during the peak of the pandemic?

Health leaders in Northern Ireland were clear from the beginning of the pandemic that Covid-19 would inevitably have an impact on health services.

At the start of the pandemic, Health Minister Robin Swann communicated that services could be 'significantly curtailed' as resources were diverted to care for coronavirus patients, clarifying that affected services would include non-urgent appointments, inpatient and diagnostic care, as well as reducing the amount of non-Covid care that GPs had to provide.<sup>42</sup>



The prioritisation guidelines on the continuation of cancer care were put together by Clinical Reference Groups as part of the Northern Ireland Cancer Network (NICaN). At the start of March, this group published a statement from oncologists and haematologists on the delivery of SACT, that stated 'disruption is inevitable'.<sup>43</sup> At the end of March, a Consultant Oncologist at the Belfast Trust told BBC Northern Ireland that some surgical cancer treatments were 'undoubtedly' being delayed.<sup>44</sup> In June, the Northern Ireland Executive published its Strategic Framework for *Rebuilding Health and Social Care Services* that acknowledged the 'severe impact' of Covid-19 on key cancer services and included an emphasis on high priority cancer services.<sup>45</sup> The Framework stated that 'work [had] now started to implement the reset of the full range of cancer services whilst taking into account the need for health and social care to respond to further Covid-19 surge(s) in 2020'. Trusts were asked to produce service rebuilding plans that covered successive three month periods from July through to March 2022.

However, the Health Minister outlined that whilst Covid-19 was still present it was 'no easy task to build services back up to pre-existing levels' and 'this will impact heavily on our capacity in the system to provide appointments, diagnostic tests, operations and a wide range of other services'.

## The impact of the first wave on cancer care

The impact on services providing diagnoses and treatment for people with cancer in Northern Ireland have been heavily impacted, and have created a backlog. The Health and Social Care Board in Northern Ireland have stated that 'Covid-19 has had a severe impact on a range of key cancer services' and that 'many procedures and diagnostic appointments have had to be postponed or delayed'. They also state that this will 'undoubtedly have an impact on waiting times for cancer treatment which are likely to persist for many months'.<sup>46</sup>

At the peak of the pandemic the number of people being diagnosed with cancer in Northern Ireland was significantly lower than it ordinarily would be. A BBC Spotlight investigation found that in April and May there were 7,500 fewer urgent referrals, which equates to around 50% of those recorded in the same period the previous year.<sup>47</sup>

The *Rebuilding and Stabilisation of Cancer Services* plan published by the Department of Health stated that 'the pressure on waiting times has been compounded this year due to the adverse impact of the Covid-19 pandemic on the system's ability to sustain services during this difficult period'. The plan acknowledged the impact of the pandemic on services stating that SACT services were able to support patients who wanted to proceed with treatment to do so, but that some radiotherapy treatment was delayed, and the impact of the Nightingale Hospital within Belfast City Hospital resulted in delays to some specialist surgery.<sup>48</sup>

## The diagnosis of cancer

Published pathology data in Northern Ireland saw 900 fewer patients' samples indicating cancer in the period between March and July this year, a 25% drop, adjusting for working weekdays in the month.<sup>49</sup> If this drop was applied to all diagnoses expected in Northern Ireland this would equate to **1,000 fewer cancer diagnoses** between March and July 2020.

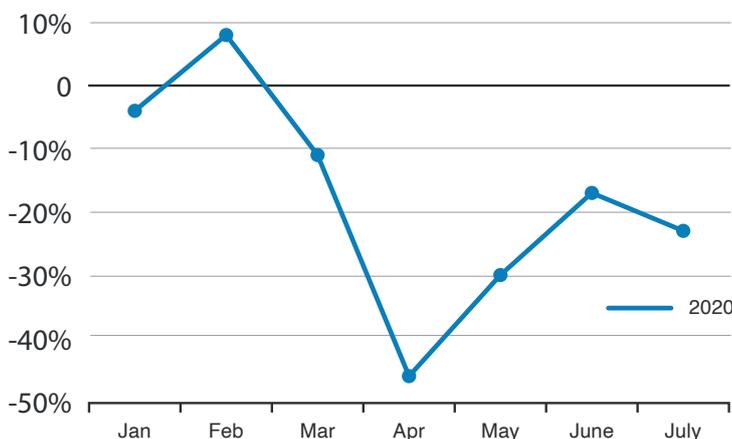
As data is not published on referrals for suspected cancer, but only for diagnoses, we are unable to calculate exactly how large the backlog of those with suspected cancers who need to be seen by diagnostic services is. But looking at the number of missed actual diagnoses, it is clear that this backlog will be significant and will need significant resource at the beginning of the cancer pathway to ensure it doesn't begin to impact on treatment outcomes.

## Diagnosis through screening programmes

At the start of April, the Health Minister announced the pausing of a number of routine screening programmes to allow for the reallocation of staff and resources to Covid-19. This included routine cervical, breast and bowel screening.<sup>50</sup> All routine screening for cancer was therefore paused for at least three months. Routine cervical screening resumed from the end of June, routine breast screening from the end of July, and bowel screening backlogs were being cleared from early summer with screening recommencing from the middle of August.<sup>51</sup>

The Health and Social Care Board in Northern Ireland acknowledged that the 'four month pause to date has resulted in a backlog of people awaiting screening' and in addition that 'screening programmes may not be able to screen the same number of people as they did before the Covid-19 pandemic' stating that it will take 'many months' to get population screening programmes up and running at 'normal levels'.

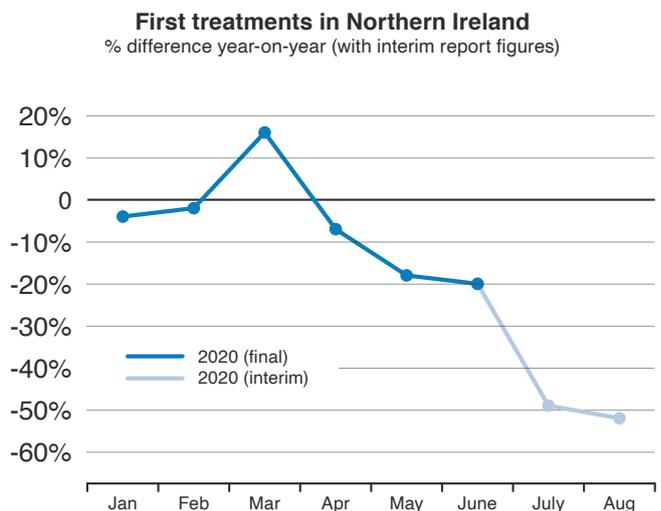
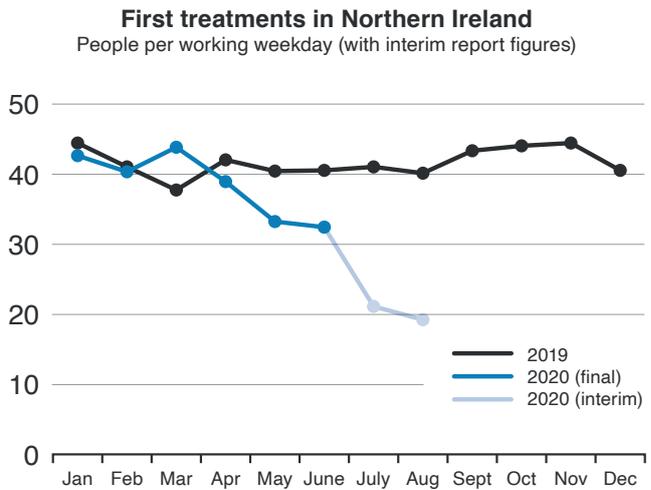
**Number of patients with pathology sample indicating cancer**  
Year-on-year % difference (2020 vs 2019)



The Health and Social Care Board in Northern Ireland acknowledge that the backlog in screening and the additional time constraints of infection control measures and social distancing mean that there is likely to be a backlog in screening for the foreseeable future. It is important that action is taken to create additional capacity to ensure that this backlog is not left static or even to grow, but is reduced as quickly as possible.

### Cancer treatment

The number of people starting first treatment in Northern Ireland was 20% behind 2019 levels in June.<sup>52</sup> Each month that the number of people starting first treatment remains at 20% less than the levels expected, the backlog for cancer services would grow by about 175 people. During the pandemic, the Department of Health opted to publish interim reports on hospital waiting times in order to show the early impact of the Covid-19 pandemic on services. Interim reports on the number of people starting first treatment for August suggests this might have dropped further to 52% of 2019 levels, suggesting that over the summer when it was hoped diagnoses and those starting treatment may increase with lesser Covid restrictions, this was not the case in Northern Ireland. As the data is not finalised, it is important to recognise that it might change, and finalised data in recent months has shown higher service use than interim reports.



## October 2020: have cancer services been restored?

In the Autumn, the Department of Health published a *Surge Planning Strategic Framework* which outlined plans to manage health services alongside surges in cases of Covid-19.

The framework acknowledged that services could have to stop again as ‘it is likely that redeployment of staff, staff absences, reduced access to theatres and patient reluctance to attend to hospital will all contribute to delays in pathways’.<sup>53</sup>

At the same time the *Rebuilding and Stabilisation of Cancer Services* policy document was published. This outlined how the Northern Ireland Department of Health plans to restore cancer services, address the backlog and develop a strong base on to which the longer term Cancer Strategy and Implementation Plan will be published and delivered. The policy document, alongside stabilisation plans for oncology and haematology, aims both to address the impact of Covid, but also longer term legacy issues, with the health and social care system. The document states the need to ‘take immediate action to increase capacity and ensure that the service is sustained over the weeks and months ahead as we face the potential for a second wave of Covid-19.’ The Department also established a Cancer Services Rebuilding Cell to implement the reset of cancer services. The action plan commits to some of the key recommendations Macmillan has outlined in this report, including use of independent sector capacity across diagnostics and surgery, regular data downloads to ‘inform service planning’, and separate plans for the stabilisation of oncology and haematology services.

Although the plan does not explicitly outline commitment to personalised cancer care, it is essential that in the push to reduce the backlog

and pressure on services in the coming months, that the Department upholds its previous commitment to delivering quality cancer care based on the needs of the individual.

The action plan also does not set out an approach to increasing urgent referrals up to pre-pandemic levels and above in order to reduce the backlog in diagnostics. This will be essential to ensuring that those who need to enter the cancer pathway do so, and as soon as possible to avoid a surge in late-stage diagnoses and poorer outcomes.

Cancer Waiting Times standards in Northern Ireland do not provide any detail on the number of referrals into the system that do not result in cancer diagnoses. It is essential that when looking to reduce this backlog, the system has an understanding of the scale of this backlog from each referral pathway in order to plan adequate surge capacity. Publication of data on referrals across the system going forward, even if only temporarily, as well as the publication of any data over the period of the pandemic that identifies the backlog of patients accessing diagnostic services in 2020, will be an important step towards increasing urgent referrals.

Macmillan also recommends that the Department of Health commits to a sustained communication campaign that encourages anyone who has symptoms to go to their GP and to encourage the uptake of screening services, with a plan to mitigate against the ongoing impact of local and national lockdowns on cancer referrals over the coming months.

## Recommendations

- The Minister of Health in Northern Ireland must prevent the cancer backlog from increasing by committing to ringfencing cancer services in light of a surge in Covid-19 cases. This includes no redeployment of staff, no delays to scans, surgery or treatment and no pausing of the screening programmes.
- The Northern Ireland *Rebuilding and Stabilisation of Cancer Services Plan* must deliver on its commitments to prioritise urgent and long term investment in oncology and haematology services which will underpin the forthcoming Cancer Strategy
- The Northern Ireland Executive should, at least temporarily, consider publishing the volume of suspected cancer referrals, where possible including the publication of historic suspected cancer referrals to the start of 2019, in order to fully understand the size of the diagnostic backlog in NI. This will enable an understanding of the drop in all referrals in comparison to pre-pandemic levels.

# THE FORGOTTEN 'C': SCOTLAND



## Key findings

### The diagnostic backlog

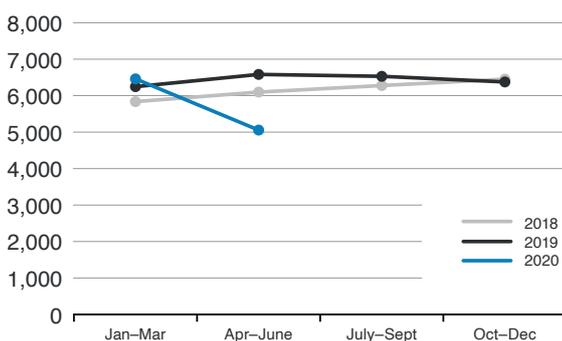
Scotland does not publish data on referrals for suspected cancer, but only on referrals that translate to diagnoses and starting treatment as part of the 62-day week standard. It is therefore not possible for us to estimate the backlog of people in Scotland who need to access diagnostic services.

However, the drop in the number of people starting treatment in Scotland outlined below is an indicator that there have likely been fewer diagnoses of cancer than there were in 2020, and that is at least in part why there is a much lower number of people going on to start treatment.

### The treatment backlog

The number of people starting treatment in Scotland was 23% behind 2019 levels between April and June, with a **backlog of 1500 fewer people**.<sup>54</sup> In actual numbers, this meant 5056 people had their first cancer treatment between April and June of 2020, compared to 6582 in the same period the previous year.

Scotland first treatment, people per quarter



It would take **7 months to treat these 1,500 patients if treatments activity levels rose to at least 10% above 2019 levels**. It would take 5 months at 20% above pre-pandemic levels. However, these projections do not include data for activity levels in July and August. If Scotland followed a similar pattern to the rest of the UK we would expect to see first treatment levels continuing to be well below 2019 comparisons for these months as well. This would likely increase the amount of time it would take to clear the backlog even further.

## What happened to cancer services in Scotland during the pandemic?

Towards the end of March, the Cabinet Secretary for Health Jeane Freeman moved NHS Scotland on to an 'emergency footing' for at least three months in order to cope with the increase in Covid-19 cases, and postponed all non-urgent elective care to free up capacity.

She was clear that 'vital cancer treatments' would continue and that NHS patients would be treated in line with their clinical priority, with the impact of Covid-19 on cancer patients having been a 'priority in all of [their] planning'.<sup>55</sup> To support health services the Scottish Government set up a National Cancer Treatment Response Group (NCTG) to provide ongoing advice and support around cancer treatment.<sup>56</sup> This group produced a series of clinical guidelines that as of the end of April 2020 were clear that 'vital cancer treatments are expected to continue'.

At the start of June, the Interim Chief Medical Officer and National Clinical Director provided an update on what services could be prioritised in the next phase of Health Board mobilisation planning, which informed the framework 'Re-mobilise, Recover, Re-design' for restarting the services that were paused due to Covid-19.<sup>57</sup> This included the prioritisation of cancer services, especially referrals and postponed treatments. Health Secretary Jeane Freeman was asked about the restoration of cancer services in the Scottish Parliament and said, 'the resumption of cancer screening and of all cancer treatments is a key area of concern'.<sup>58</sup> It was clear, that the impact of pausing non-essential services across the health system and its impact on cancer care was recognised by decision-makers as a significant concern.

To support the next stage of service restoration, the Scottish Government published its framework for the recovery of cancer services in Scotland in June. The framework set out a list of directives to Health Boards, that included the need to provide adequate critical and intensive care support capacity, the opportunity to send patients to other Health Boards or independent sector hospitals for care, and that Covid-19 'green sites' should be used for cancer surgery 'where possible'.<sup>59</sup>

# The impact of the first wave on cancer care

## The impact on diagnosis of cancer

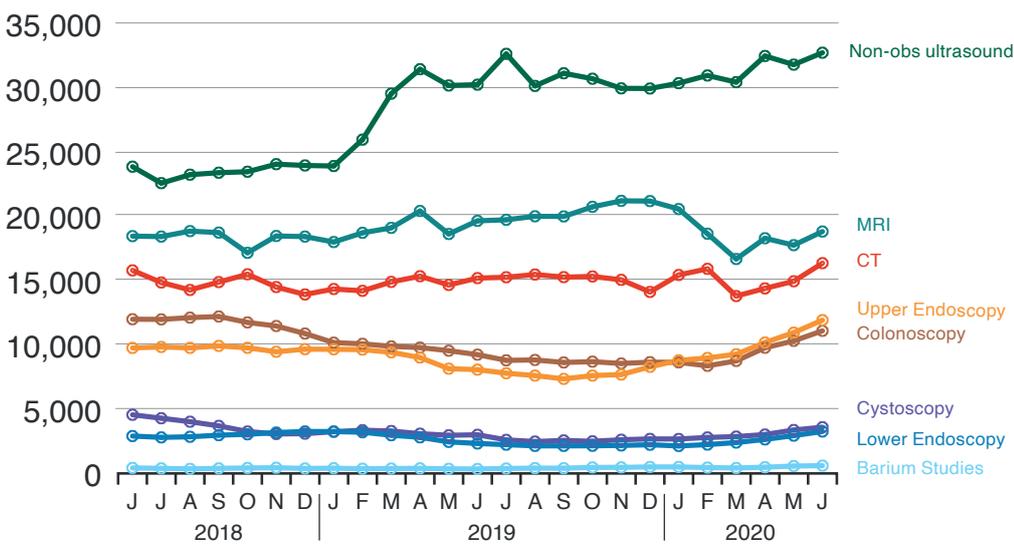
The peak of the pandemic saw a significant impact on cancer services in Scotland with a dramatic fall in urgent referrals for suspected cancers. In April, the Interim Chief Medical Officer said there had been a 72% reduction in urgent suspected cancer referrals from primary care.<sup>60</sup>

Despite a drop in referrals, the waiting lists for key diagnostic tests for cancer grew in Scotland over the period of the pandemic. This is likely to be because of the challenges in undertaking certain procedures during the Covid-19 pandemic because of the additional infection control measures needed slowing the number of patients the system can manage. It could also be because of the impact of Covid-19 on the capacity of staff and other necessary resources.

The biggest impact was on endoscopy, where the waiting lists in Scotland grew by 33% between the end of February and the end of June. The waiting lists for imaging procedures also grew by 4% over the same period.

Delays in access to diagnostic tests that can identify cancer will create a bottleneck from referral through to starting treatment and will mean a backlog at the front end of the system builds up even if adequate capacity for treatment and care is available.

Scotland: waiting list for diagnostics tests at month end



## Diagnosis through screening programmes

At the end of March, the Scottish Government formally paused screening programmes including breast screening, cervical screening and bowel screening in order allow ‘healthcare staff [to] be re-allocated to support other essential services.’<sup>61</sup> The then-Chief Medical Officer was clear that there were risks to individuals through delayed diagnosis through screening programmes, but that these risks ‘need to be weighed up in the context of the pressures on the NHS in Scotland posed by Covid-19’.

Scotland has now re-started screening services. From the end of June and through July, the Scottish Government announced the resumption of breast screening, cervical screening and endoscopy services.<sup>62, 63</sup> The Scottish Government also announced additional investment to address the patient backlog for endoscopies in July, which they estimated at the time was about 19,000 patients recorded as waiting for a diagnostic endoscopy.<sup>64</sup> There was also worrying reports over the summer that screening services were taking longer than hoped to fully re-start, as the Scottish Government confirmed that nearly 400,000 breast, bowel and cervical screenings were postponed since lockdown began.<sup>65, 66</sup> The Scottish Government announced on the 12th of October that bowel screening had resumed.<sup>67</sup>

When the Scottish Government paused screening programmes, they estimated the numbers that would be affected every quarter-year based on the most recent information available. These estimates stated that within a three-month period, 248,177 patients would receive bowel screening, of which 220 would be diagnosed with cancer; 46,596 patients would receive breast screening, of which 291 would be diagnosed with cancer; and 101,963 patients would receive cervical screening, of which 341 would be diagnosed with invasive cancer.<sup>68</sup>

Following an understanding that cervical and breast screening were both paused for a minimum of three months, and that bowel screening was paused for a minimum of six months, this would mean at least 644,793 people would have missed out on screening over the period the programmes were paused. It is likely to be higher as breast and cervical screening were not both fully operational from the 1 July.

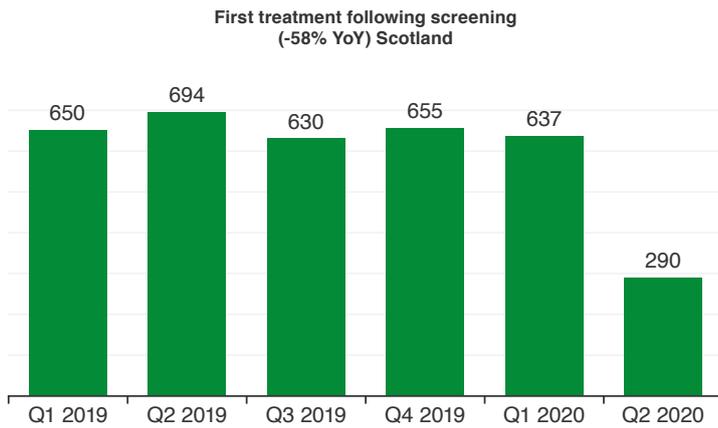
% of first treated from screening  
(-46% YoY) Scotland



## The impact on treatment

Between April and June 2020, at the peak of the pandemic, there was a 20% drop in the number of people starting treatment for cancer within 62 days of urgent referral compared to last year, meaning 649 fewer people began treatment. Worryingly, 1,324 fewer people were treated within the 31-day limit from decision to treat to treatment compared to last year (21% lower than last year). These figures demonstrate the significant impact of people being too worried to seek care and investigate symptoms for fear of being exposed to Covid-19 or being a burden on the NHS.

The number of people in Scotland who started treatment after being diagnosed via screening was 58% lower than expected during April-June 2020. This indicative again of the impact on diagnoses of pausing screening, with only 290 (6%) people starting treatment coming through screening programmes in April – June, when 694 (11%) of those starting treatment came through screening programmes in the same period last year.



## October 2020: have cancer services been restored?

At the start of August, the Scottish Government updated guidance on the recovery of cancer surgery, classifying cancer patients by priority in order to support Health Boards to get through the backlog in cancer patients needing surgery.<sup>69</sup>

It is based on the principles of equity of access that includes working across boards, and states Health Boards should provide weekly updates to the National Cancer Treatment Group on cancer patients in the system who have had or are awaiting surgery. These regular updates will provide service planners with an understanding of the scale of the backlog in surgery and allow them to plan services accordingly.

The guidance provided a picture of what the Scottish Government understood the backlog to be at the time of publication (the end of August). It stated that the number of suspected cancer referrals waiting for scans, endoscopy and screening was 2,000 and the backlog of cancer patients impacted by Covid-19 waiting for surgery was 500. Macmillan would encourage the NCTG to publish updated and aggregated data on the cancer backlog so that there is better understanding of the current scale of the backlog.

It also estimated that surgery services would be operating in most boards at around 60% of pre-Covid levels for at least two years and 'perhaps longer if there are further surges in Covid-19 incidence'. The guidance also directs Health Boards to upscale elective cancer surgery to meet local demands and to 'equitably' address the backlog accrued during the Covid-19 outbreak but recognises this would be a 'challenging task'. More recently, the Scottish Government has now moved on from the 60% figure to stating they are back to full capacity on elective surgery.

At the time of this report's publication we are awaiting the publication of the Cancer Recovery Plan 2020–2023 from the Scottish Government. We hope it will address many of the issues we have set out.

### Recommendations

- The Scottish Government Cancer Recovery Plan 2020–2023, which is due to be published shortly, must include clear details on how to deal with the surge in cancer diagnosis and treatment that is expected following the significant drop in referrals during the peak of the Covid-19 pandemic
- The Cabinet Secretary for Health must prevent the cancer backlog from increasing by committing to ringfencing cancer services in light of a surge in Covid-19 cases. This includes no redeployment of staff, no delays to scans, surgery or treatment and no pausing of the screening programmes.
- The Scottish Government must follow through on its commitment made in June 2020 for routine testing for Covid-19 of cancer staff across Scotland to prevent the risk of delays or cancellations to treatment caused.
- The Scottish Government and NHS Scotland should, at least temporarily, consider publishing the volume of suspected cancer referrals, where possible including the publication of historic suspected cancer referrals to the start of 2019, in order to fully understand the size of the diagnostic backlog in Scotland. This will enable an understanding of the drop in all referrals in comparison to pre-pandemic levels.

# Conclusion

The Covid-19 pandemic is unprecedented and profound. Cancer care, and the disruption to it in 2020, impacts hundreds and thousands of people, and it's important that as the pandemic continues, lessons are learnt, and adaptations made.

We thank everyone in the NHS for their incredible work in what may be the greatest challenge they've ever faced. It's vital now that Governments across the UK recognise that cancer care had challenges before the pandemic, and continues to do so now.

As part of the 'ecosystem' of cancer, we will do everything we can to encourage people to come forward to get checked for cancer, as we know this is vital to catch up on the backlog. But it's also our role to ensure that cancer services have everything they need to test, treat and care for these many thousands of people in the months ahead.

And finally, and most importantly – we also recognise the impact the pandemic has had on thousands of people with cancer. Thank you for sharing your experiences and campaigning with Macmillan Cancer Support, so we can raise your voices to decision makers and make sure cancer doesn't become the Forgotten 'C'.

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- 2 Macmillan Cancer Support. *These projections are calculated by looking at the latest month's year-on-year percentage difference in activity, how much that percentage difference had improved from the previous month and then plotting that same trajectory forwards each successive month up to a maximum of 10% or 20% above pre-pandemic levels. Activity above 0% indicates higher activity than pre-pandemic and a reduction in the backlog. Activity is defined as number of people with suspected cancer seeing a specialist following an urgent referral from a GP per working weekday. Provider-based Cancer Waiting Times for August 2020 (Provisional), NHS England.*
- 3 Macmillan Cancer Support. *These projections are calculated by looking at the latest month's year-on-year percentage difference in activity, how much that percentage difference had improved from the previous month and then plotting that same trajectory forwards each successive month up to a maximum of 10% or 20% above pre-pandemic levels. Activity above 0% indicates higher activity than pre-pandemic and a reduction in the backlog. Activity is defined as number of people starting first definitive cancer treatment following a decision to treat per working weekday. Provider-based Cancer Waiting Times for August 2020 (Provisional), NHS England.*
- 4 Note: Percentage figures from reference 1, rounded to the nearest percentage point, were applied to the estimated 3 million people living with cancer in the UK. 3 million figure is derived from 2019 complete prevalence ([Macmillan-NCRAS Cancer Prevalence Project](#)). This is projected forwards using the UK growth rates in [Maddams et al. \(2012\)](#), resulting in an estimated 3 million people living with cancer in the UK. This includes all people who have ever had a cancer diagnosis, some people in this group may no longer consider themselves to be living with cancer.
- 5 Note: Percentage figures from reference 1, rounded to the nearest percentage point, were applied to the estimated 3 million people living with cancer in the UK. 3 million figure is derived from 2019 complete prevalence ([Macmillan-NCRAS Cancer Prevalence Project](#)). This is projected forwards using the UK growth rates in [Maddams et al. \(2012\)](#), resulting in an estimated 3 million people living with cancer in the UK. This includes all people who have ever had a cancer diagnosis, some people in this group may no longer consider themselves to be living with cancer.
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Being told ‘you have cancer’ can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you’re still you. We get that. And, after over 100 years of helping people through cancer, we get what’s most important: that you’re treated as a person, not just a patient.

It’s why we’ll take the time to understand you and all that matters to you, so we can provide the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We’re here to help you find your best way through from the moment of diagnosis, so you’re able to live life as fully as you can.



**For information, support or just someone to talk to,  
call 0808 808 00 00 or visit [macmillan.org.uk](https://www.macmillan.org.uk)**