

Scared & Forgotten

An inquiry into the impact of COVID-19 on blood cancer services



All-Party Parliamentary Group
on Blood Cancer



All-Party Parliamentary Group
on Stem Cell Transplantation

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March 2022

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This report was compiled by Blood Cancer UK and Anthony Nolan who provide the Secretariats to the All-Party Parliamentary Group on Blood Cancer and the All-Party Parliamentary Group on Stem Cell Transplantation and Advanced Cellular Therapies respectively.

Foreword

In March 2020, the country was hit by the worst pandemic in a hundred years, changing all our lives dramatically. In many ways, people living with blood cancer have been uniquely impacted by the COVID-19 pandemic.

Whilst in the last decade there has been hard-won progress on blood cancer survival,¹ the pandemic has placed this in peril, with the very real prospect that survival rates in the UK could decline for the first time.

As Chairs of the All-Party Parliamentary Groups on Blood Cancer and Stem Cell Transplantation and Advanced Cellular Therapies, we wanted to uncover the extent of the deep and ongoing impact of the pandemic on the blood cancer community. From increasing waiting times to changes to treatment pathways, it is clear this has been a major shock to the system that has ramifications for the physical and emotional wellbeing of people living with blood cancer, their families, and the NHS staff caring for them.

It remains to be seen what the long-term outcomes will be. As the evidence submitted to this inquiry attests, much depends on the NHS being equipped with the resources it needs to address the growing cancer backlog which threatens to persist for years to come.

We hope the recommendations of this report will serve to support the efforts underway to recover blood cancer services and meet rising demand, by highlighting the experiences and priorities of patients, families, carers, and healthcare professionals.

We are grateful to all those who contributed evidence, during what continues to be a challenging period for the whole of the blood cancer community. We are particularly indebted to the people living with blood cancer who shared their experiences with us at such a testing time.

It is of vital importance that the needs of people with blood cancer are not overlooked as the NHS sets the pathway to recovery from the pandemic. Our hope is that the recommendations set out in this report shape the future of blood cancer services and ensure that the needs of people living with blood cancer in this context remain firmly on the NHS and political agenda.



Henry Smith



Mark Tami

Henry Smith MP and Mark Tami MP

Chairs of the APPG on Blood Cancer and the APPG on Stem Cell Transplantation and Advanced Cellular Therapies

¹ *Blood Cancer UK, Blood cancer survival rising faster than other common cancers, June 2019 <https://bloodcancer.org.uk/news/blood-cancer-survival-rising-faster-other-common-cancers/>*

Executive summary

The coronavirus pandemic has had an unprecedented impact on health services and outcomes globally, not least in the provision of cancer care. An increasing body of evidence reveals that the impact has been experienced acutely by the blood cancer community – and continues to be felt after two years.

This inquiry aimed to gather and analyse evidence on the pandemic's impact on blood cancer services across England and propose recommendations to support Government and NHS efforts to ensure the needs of people with blood cancer are met. The inquiry received written submissions and heard oral evidence from nearly 70 individuals and organisations, including people living with blood cancer, their carers and families, healthcare professionals, patient organisations and charities.²

The report is divided into four sections, exploring:

- Leadership during the pandemic
- The impact of the pandemic on blood cancer referrals, diagnosis and waiting times
- The experiences of people with blood cancer of using NHS services during the pandemic
- The blood cancer workforce

People with blood cancers are at very high risk from COVID-19 and represent a large proportion of the country's immunocompromised population. However, there is no cross-governmental strategy for supporting this group of people, and communications around guidance have been inconsistent.

Despite being the fifth most common cancer³, referrals and diagnoses for blood cancer have historically lagged disproportionately. Prior to the pandemic, a higher proportion of people with blood cancer were diagnosed via emergency admission than most other common cancer types.⁴

Evidence captured through the inquiry has shown that the pandemic has exacerbated these issues. Early diagnosis is important to improve treatment options and the quality of life of people with blood cancer and their families, yet between May and September 2020, the most common route to diagnosis was through people arriving in hospital A&E departments.⁵ In this early wave, new diagnoses and referral rates fell dramatically.⁶ This resulted in a significant backlog of cases which has since led to record waiting lists and will likely result in a wave of late diagnoses.

² See Appendix for further details

³ Blood Cancer Dashboard, 2020 <https://bloodcancerdata.co.uk/>

⁴ Blood Cancer Alliance, *The unmet needs of people with blood cancer across the United Kingdom, November 2021* <https://static1.squarespace.com/static/5b98cdc612b13fdd2982129d/t/619664793014f77536aeaf5d/1637246073957/The+Forgotten+Fifth+Evidence+Review.pdf>

⁵ The National Disease Registration Service, *COVID-19 rapid cancer registration and treatment data new haematological cancer diagnoses by route to diagnosis, August 2021* www.cancerdata.nhs.uk/covid-19/rcrd

⁶ Evidence submitted to the joint inquiry by Cancer Research UK, July 2021

Throughout the inquiry, we heard about the changes to services brought on by the pandemic. While some have been widely welcomed by the blood cancer community, such as the introduction of new medicines, others have received much more mixed feedback, such as the adoption of remote consultations. There has also been a reduction in access to clinical trials during the COVID-19 peaks – a very worrying trend. It is important that the experiences and concerns of people affected by blood cancer during this period are reflected on and the lessons learned are applied going forward.

All the above has taken place against the backdrop of severe and longstanding workforce shortages within the NHS, and blood cancer services specifically. The pandemic has heightened this pressure with a third of the blood cancer professionals surveyed as part of this inquiry stating that there are ‘major’ staffing shortfalls.⁷ If left unchecked, these staffing issues have the potential to gravely impact patient experience and potentially even the quality of care received.

Overall, while NHS staff at the frontline have made incredible efforts to keep blood cancer services going, it is clear that there is a real need to ensure that blood cancer services are equipped with the additional resources and support they need to tackle the growing backlog and deliver high-quality care. Without sufficient resource and attention from Government, the long-term impact of COVID-19 on the blood cancer community will be devastating. It is vital that action is taken now to mitigate this impact and ensure blood cancer services recover from the pandemic.

A coordinated and systematic strategy is required to restore and improve blood cancer service delivery and patient outcomes. Our key recommendations for the UK Government and NHS England to achieve this are in summary:

Greater strategic leadership

A consistent finding throughout the inquiry is the clear need for a strategic response between the Department for Health and Social Care and NHS England. This starts with a long-term strategy for immunocompromised people including the coordination of COVID-19 related support, communications and guidance for immunocompromised people, and a public awareness campaign of the ongoing risk this group of people face.

Improved data collection and evaluation

Robust data capture on an ongoing basis is a critical factor in improving patient outcomes and setting a standard of best practice. As soon as is feasible, the NHS should evaluate blood cancer outcomes during the pandemic (such as stage of diagnosis and survival compared to before the pandemic), to inform where additional targeted attention is required.

Specific blood cancer commitments and investment

We encourage NHS England to set clearer and more ambitious targets for blood cancer service delivery and patient outcomes over the longer term, to ensure that progress is made. This can only be realised with additional resource from the Government to meet increased demand, tackle the backlog and ensure equitable access to patient care, including a commitment to increase and protect haematology capacity in the NHS.

⁷ Evidence submitted to the joint inquiry by the Blood Cancer Alliance, August 2021

Leadership

People living with blood cancer are one of the most at-risk groups from COVID-19. Additionally, their weakened immune systems mean they are less likely to mount a response to COVID-19 vaccines – in some types of blood cancer, research has shown vaccine response rates as low as 25% for people on certain types of anti-cancer treatment.⁸ The approximate 230,000 people with blood cancer in England make up a significant proportion of all severely immunocompromised people.

In the first six months of 2021, 13.1% of COVID-19 deaths in fully vaccinated people were those who were immunocompromised.⁹ This figure would be much higher if this group had not been taking significant precautions – with many still shielding – since the beginning of the pandemic.

As the vaccine rollout began in December 2020, there was limited acknowledgement in official Government communications that vaccination would not offer a solution to the risk facing immunocompromised people. Subsequent planning and communication around the lifting of restrictions did not sufficiently consider the continued high risk the virus posed to this group of people.

A key concern that charities have heard is that people living with blood cancer are feeling scared and forgotten during the pandemic. This fear grew exponentially as restrictions were significantly reduced in England in July 2021. Masks were no longer compulsory and Government communication and guidance on

social distancing and shielding was judged to be inconsistent and unclear.

People living with blood cancer and their families no longer felt safe, with many feeling as though they had been left in limbo with no end in sight.

“The decision to remove the obligation to wear face masks in enclosed spaces... leaves me very vulnerable, in that it restricts my movements to outdoor spaces only...I must remain in lockdown for the unforeseeable future.” – Evidence submitted to the inquiry from a person living with blood cancer.

“We will not escape on ‘Freedom Day’. In fact, we will be tied down further. We have no choice now” – Evidence submitted to the inquiry from a person living with blood cancer.

“Now we have no endpoint [of voluntary shielding] so you feel like you’re on the treadmill as a hamster and you can’t get off” – Evidence submitted to the inquiry from a person with a stem cell transplant.

This has had an undeniable psychological impact, not least on the carers and family members of those at risk, including young children, who must take extra precautions. Their experience is in stark contrast to the dominant jubilant ‘Freedom Day’ rhetoric of the summer

⁸ Blood Cancer UK, Vaccine Research Collaborative, December 2021

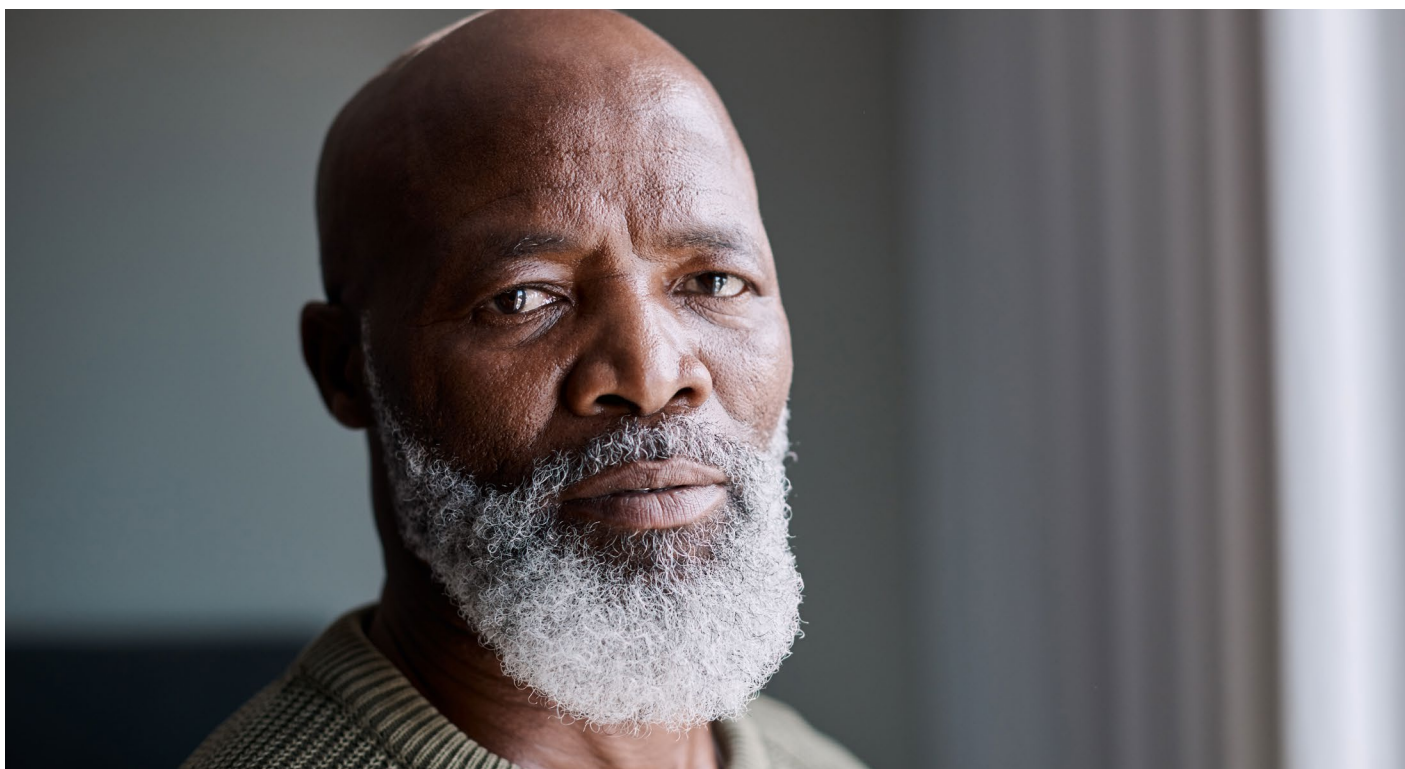
⁹ Office for National Statistics, Deaths involving COVID-19 by vaccination status, England: deaths occurring between 2 January and 2 July 2021, September 2021 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19byvaccinationstatusengland/deathsoccurringbetween2januaryand24september2021>

of 2021. Scientists we heard from as part of the inquiry called for a sustained public health campaign from the Government, with improved messaging about protecting society as a whole, including those who remain at high risk.

A long-term plan is urgently needed to ensure that people living with blood cancer are protected from this virus as we adapt to live with it. This includes ongoing, clear guidance and support for those at high risk, and improved public awareness. Such a plan can only be achieved with strengthened leadership and accountability from the UK and devolved governments, and the NHS. Failure to do so will have significant ramifications for the physical and psychological health of the blood cancer community.

Recommendations

1. A long-term Government and NHS England strategy is needed for immunocompromised people, due to their continued risk from COVID-19.
2. The Government should work with patient organisations, clinicians, and employers to produce clear and meaningful guidance for immunocompromised people.
3. The Government and NHS England should create specific roles dedicated to coordinating the support available to immunocompromised people and representing these people in decision-making.
4. There is an urgent need for improved Government and NHS England communications to immunocompromised people. Dedicated guidance and information should be made available via hospitals, NHS, and Government websites, and during Government press briefings.
5. The Government should consider launching a public awareness campaign to educate the general population on the risks still facing immunocompromised people and how best to protect them.



Blood cancer referrals, diagnosis and waiting times

Evidence submitted to this inquiry has illustrated the dramatic impact of the pandemic on blood cancer referrals and diagnoses.

Even before the pandemic, blood cancer patients struggled disproportionately to receive timely referrals. The pandemic has exacerbated the persistent challenges with referral and early diagnosis.

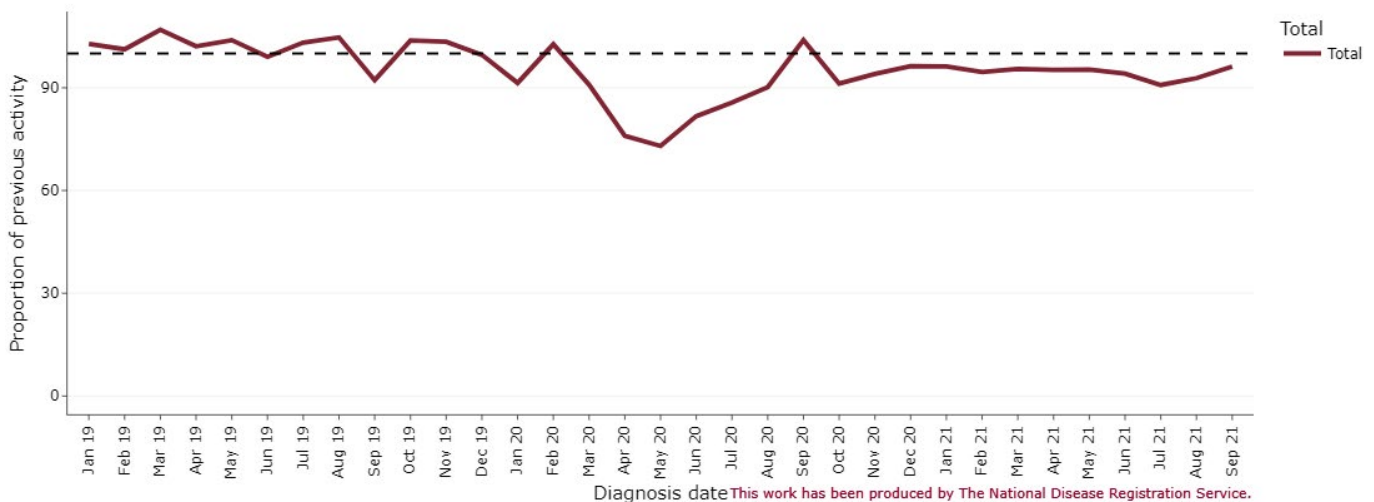
There is grave concern that the steep drop in referrals that occurred in the first wave of the pandemic, combined with record-length waiting times, is driving a wave of late diagnoses, and leaving people with blood cancer with fewer treatment outcomes and poorer prognosis.

Diagnoses

The first waves of the pandemic caused a sharp drop in new blood cancer diagnoses, with the greatest fall in April and May 2020 when 27% fewer diagnoses were made compared to the same months in 2019. Overall, from April to December 2020 there were around 2,200 (13%) fewer blood cancers diagnosed in England compared to the same period in 2019.¹⁰

Analysis from Macmillan has estimated that in total there are over 47,000 fewer than expected cancer diagnoses in the UK since March 2020.¹¹ Among the cancer types with the highest rates of “missing” diagnoses are two blood cancers – myeloma (14% reduction) and lymphoid leukaemia (12% reduction).

Total new haematological cancer diagnoses, England, January 2019 to September 2021¹²



¹⁰ Evidence submitted to the joint inquiry by Cancer Research UK, July 2021

¹¹ Macmillan Cancer Support, Mountain of almost 50,000 people still missing a cancer diagnosis in the UK as NHS already struggling to cope with existing demand, November 2021 <https://medium.com/macmillan-press-releases-and-statements/mountain-of-almost-50-000-people-still-missing-a-cancer-diagnosis-in-the-uk-as-nhs-already-f533f178cef3>

¹² The National Disease Registration Service, COVID-19 rapid cancer registration and treatment data – new haematological cancer diagnoses, September 2021 www.cancerdata.nhs.uk/covid-19/rcrd

Referral rates

Accompanying this was a fall in the overall number of urgent suspected cancer referrals, which in April 2020 declined to just 40% of pre-pandemic levels.¹³

Urgent suspected referrals for blood cancer have since recovered to 95% of pre-pandemic levels cumulatively from March 2021 to August 2021, and were at 105% of pre-pandemic levels in August 2021.¹⁴ This has led to record waiting lists as the NHS struggles to meet this “pent up” demand.

Potential drivers of falling referrals

- People with potential symptoms of blood cancer being hesitant to attend healthcare settings during the first peak of the pandemic.
- Reduced capacity in community and diagnostic services to assess and refer patients.
- Blood cancer can be challenging to diagnose due to its non-specific symptoms. COVID-19 has added additional complexities to the identification of blood cancer, partly due to its symptoms overlapping with COVID-19.

Waiting times

In October 2021, only 71% of suspected acute leukaemia urgent cancer referrals and 90% of other suspected blood cancer referrals were seen within two weeks.¹⁵ The performance target across all cancers is 93%.

Even more worrying is that only 55% of blood cancer diagnoses (excluding acute leukaemia, for which the figure was 58%) via the urgent suspected cancer pathway in October 2021 were told of their blood cancer diagnosis within 28 days.¹⁶ NHS England does not report data on the number of people with blood cancer who started treatment within 31 days of their diagnosis and within 62 days of their urgent referral. However, across all cancers, the number of people waiting more than a month to start treatment was at the highest-ever number on record.¹⁷

People living with blood cancer whose care was delayed shared with the inquiry their “mental anguish and anxiety” caused by experiencing long waiting lists and the severe impact this has had on their mental health.

¹³ Evidence submitted to the joint inquiry by NHS Cancer Programme, September 2021

¹⁴ Ibid

¹⁵ NHS England, *Two Week Wait – By Suspected Cancer (Provider Data), October 2021* <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2021-22-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-october-2021-22-provisional/>

¹⁶ NHS England, *28-Day Faster Diagnosis – By route and suspected cancer, October 2021* <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2021-22-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-october-2021-22-provisional/>

¹⁷ Independent, *NHS waiting list at record high as 5.8 million still waiting for treatment, November 2021* <https://www.independent.co.uk/news/health/nhs-waiting-list-update-treatment-b1955721.html>

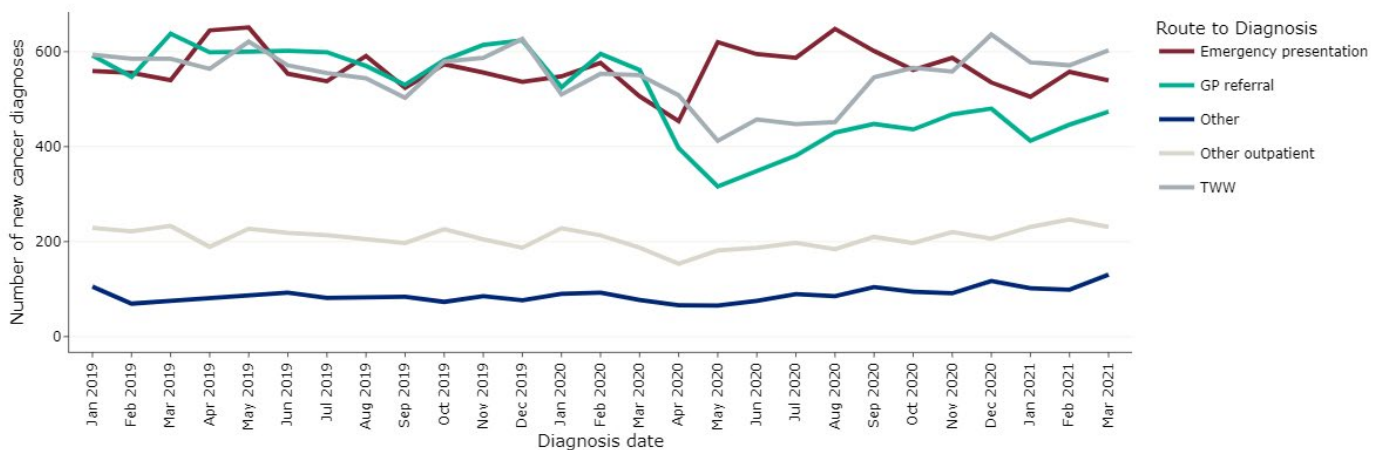
Emergency presentations

Before the pandemic, the proportion of blood cancer diagnoses made through emergency presentation was roughly in line with those via GP and urgent suspected cancer referrals. This is in contrast with the period from May 2020 to September 2020, during which time the most common route to diagnosis was through emergency presentation (36.2%), in other words through people arriving in A&E.¹⁸ This was followed by two-week wait (27.3%) and GP referral (22%). Although the number of emergency route presentations has since decreased, as of March 2021, the latest data point available, more blood cancer diagnoses were still being made via emergency presentation (27.3%) than GP referrals (23.9%).¹⁹

“Late presentations during the pandemic will give rise to poor outcomes (patients diagnosed through admission rather than outpatient referral carry a significantly reduced survivorship likelihood) whilst presentation with advanced-stage disease will give rise to both greater use of healthcare resources and psychological burden for those affected.” – UK Myeloma Forum

It is crucial that more people are diagnosed with blood cancer at earlier stages of their disease. 40% of people with blood cancer live for three years or more if they are diagnosed in emergency settings, compared to 77% of those diagnosed via their GP.²⁰

New haematological cancer diagnoses by route to diagnosis, England, January 2019 to March 2021²¹



This work has been produced by The National Disease Registration Service.

¹⁸ The National Disease Registration Service, COVID-19 rapid cancer registration and treatment data new haematological cancer diagnoses by route to diagnosis, August 2021 www.cancerdata.nhs.uk/covid-19/rcrd

¹⁹ Ibid

²⁰ Blood Cancer UK, Over a quarter of blood cancer cases only diagnosed after emergency admission, October 2019 <https://bloodcancer.org.uk/news/over-quarter-blood-cancer-cases-only-diagnosed-after-emergency-admission/>

²¹ The National Disease Registration Service, COVID-19 rapid cancer registration and treatment data new haematological cancer diagnoses by route to diagnosis, August 2021 www.cancerdata.nhs.uk/covid-19/rcrd

We recognise that the NHS has made commendable progress in recovering referrals across all cancer services, including blood cancer. However, we are concerned that there does not appear to be a specific focus on the negative impact of the pandemic on blood cancer services.

There is clearly a growing backlog in blood cancer treatment which requires urgent action to address. While additional funding to tackle the overall NHS elective care backlog is welcome, specific action is needed to:

- Reduce the number of blood cancers diagnosed via emergency routes; and
- Tackle waiting lists for blood cancer treatment.

Recommendations

1. NHS England should track, on a monthly basis, the number of people diagnosed with blood cancer via emergency routes, and at later stages, in each region, cancer alliance, and ICS.
2. This data should be used to inform specific action to reduce the percentage of blood cancers diagnosed via emergency routes and at later stages, for example, targeted GP education and specific signposting to local Rapid Diagnostic Centres (RDCs). This would also allow for greater sharing of good and successful practice.
3. We welcome the progress that NHS England has made in rolling out RDCs, which are an important tool to detect blood and other cancers earlier. However, it remains unclear how well current RDCs are performing in diagnosing blood cancers earlier in the pathway. NHS England should provide an update on its evaluation of RDCs and enable those that are performing well in diagnosing blood cancers earlier to share their learnings nationally. We also recommend that RDCs are provided with additional resource to pilot self-referral and direct-to-test models as soon as is feasible.
4. Although urgent referrals for suspected blood cancer are now higher than pre-pandemic levels, it remains important to ensure that public awareness and confidence in the NHS remains, and this should not exclude potential signs and symptoms of blood cancer. We recommend that NHS England considers the merits of including a blood cancer-specific awareness campaign under its highly successful “Help Us, Help You” banner. This should be accompanied by GP education to support primary care referrers to spot the potential signs and symptoms of blood cancer.
5. We would encourage the Department of Health and Social Care and the NHS England Cancer Programme to use the “reset” opportunity from the pandemic to create more ambitious objectives for cancer services in general, and blood cancer services in particular. Cancer outcomes continue to lag behind comparable nations²² and performance standards (such as targets for cancer waiting times) were not being met even prior to the pandemic. COVID-19 has provided an opportunity to re-assess the ambition set out in the NHS Long Term Plan with a view to being bolder.

²² *Lancet Oncology, Cancer survival in Europe 1999-2007 by country and age: results of EURO-CARE-5 - a population-based study, January 2014* [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70546-1/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext)

The impact of service changes on patient experience

The need to protect people with blood cancer and staff from becoming infected with COVID-19 has necessitated rapid changes to how blood cancer services are delivered; many of which are likely to endure over the longer term.

Throughout our inquiry, we heard from people living with blood cancer and their families about how these changes have impacted their experience of using blood cancer services. While some of the changes have been welcomed by the community, others – such as the limitations on hospital visitors – have had profoundly distressing impacts.

Introduction of new medicines and pathways

One of the changes widely welcomed by the blood cancer community has been the introduction of new treatments which can reduce time spent in hospital. In some cases, these medicines were provided by manufacturers free of charge to the NHS before their approval. It is estimated that around 81% of blood cancer patients were converted from intravenous to subcutaneous injections between June and September 2021.²³ This change has helped avoid prolonged hospital stays owing to the reduced need for monitoring and is generally a more convenient treatment experience for patients.

Table 1: Blood cancer treatments introduced during the pandemic (as of July 2021)

Disease	Drug /Regimen Changes
AML	Venetoclax with low dose cytarabine/ azacitidine instead of standard induction chemotherapy
Lymphoma (Hodgkin's)	Nivolumab earlier in treatment pathway post brentuximab to replace salvage chemotherapy
Lymphoma (Hodgkin's)	Brentuximab earlier in treatment pathway to replace salvage chemotherapy
Lymphoma (NHL)	Switch intravenous rituximab to subcutaneous rituximab in follicular lymphoma patients
Lymphoma (NHL- Mantle Cell)	Ibrutinib 1st line instead of chemotherapy
Lymphoma (NHL- Mantle Cell)	Tecartus introduced as a new CAR-T technology
Myeloma	Oral pomalidomide with dexamethasone as 2nd or 3rd line therapy instead of IV treatment
Myeloma	1st line lenalidomide and dexamethasone for transplant eligible
Myeloma	2nd line lenalidomide patients with not treated with a 1st line bortezomib-regimen
Myeloma	Ixazomib with lenalidomide and dexamethasone as 2nd line therapy instead of IV treatment
GVHD	Ruxolitinb as an alternative to other treatments for GVHD after allogeneic stem cell transplant

²³ Evidence submitted to the joint inquiry by Janssen, August 2021

The pandemic has also changed treatment pathways. For example, many people with myeloma, a type of chronic, incurable blood cancer, have been placed on a type of treatment known as “maintenance therapy” as a short-term alternative to a stem cell transplant, where previously transplant would have been the preferred option. There is very little, if any, evidence of the impact of these kinds of changes on the quality of life or survival of people with blood cancer.

Care closer to home

The NHS also quickly adopted remote consultations, community-based diagnostics, and greater access to chemotherapy at home as ways to reduce the number of hospital visits, alongside the implementation of enhanced Infection Prevention and Control measures.

The people living with blood cancer and carers that we heard from had mixed feelings about the introduction of remote consultations. While many appreciate the benefits of telephone and video consultations, such as less exposure to infection, reduced travel costs and time spent, others also told us that they were concerned that people who had yet to be diagnosed with blood cancer might be missed if not seen in person.

“Telephone consultations simply don’t work for complex diseases such as blood cancer.” – Evidence submitted to the inquiry from a person living with blood cancer.

The sole use of remote appointments also reduced access to clinical nurse specialists (CNSs) and other healthcare professionals, leaving people with fewer opportunities for both casual and formal psychological support.

“It’s often intimidating to have a call with a specialist consultant, and they are always in a hurry. It would be nice to get a “how are you?” call from a nurse who has time to listen to any concerns.”

– Evidence submitted to the inquiry from a person living with blood cancer.

There is also a risk that certain groups are disproportionately impacted by remote consultations. For example, people without access to an internet connection or telephone line may have been excluded from accessing care.

These concerns are echoed by blood cancer NHS staff. A survey conducted by the British Society for Haematology (BSH) highlighted that 93% of physicians felt the pandemic has reduced their ability to communicate sensitive information face to face.²⁴ Such appointments are an important route for people to raise concerns and questions about their health and care. Reduced in-person access to clinicians increases the risk of missing clinically relevant details such as weight loss, enlarged nodes and discolouration of nails, which may not be alarming enough for people to raise during remote consultations, but which could have been observed and investigated further by doctors and nurses.

Visitation policy

We recognise and appreciate the urgent need to protect NHS staff and vulnerable patients from infection, which guided NHS Trusts’ decision-making on visitation policy in the initial phases of the pandemic. However, there must also be an appraisal of the consequences of these policies on patients, particularly on the people with blood cancer who died during the pandemic, and their loved ones.

²⁴ British Society for Haematology, membership survey, November 2020 <https://b-s-h.org.uk/membership/membership-survey-2020/>

The family of Ollie Bibby, who died from blood cancer during the pandemic, feel let down by the imposition of such limited visiting opportunities. They described how their son's mental health was severely impacted by being alone in hospital for long stretches and would call home, "distraught". The family shared how they feel "cheated" that they couldn't spend valuable time with him in his final weeks.

"It felt like I was putting him in with the lions. It felt unbearable as we walked away."²⁵

Through the course of this inquiry, we heard from family members who were unable to see their loved ones in hospital even after it became evident that they were approaching the end of their life.

It is important that there is a unified policy approach across trusts regarding visitation. Crucially, now that rapid COVID-19 testing is readily available, testing should be used to allow visitation for those at the end of life and for those who receive traumatising diagnoses.

While we hope that experiences such as those of Ollie Bibby and his family were the exception rather than the norm, there is no way of telling how many families across the country were put in similar circumstances. As blood cancer services now embed new ways of working, it is important that compassionate and person-centred care is prioritised.

Reduced access to clinical trials

During the height of the pandemic, most clinical trials were suspended, and the

continuing constraints on NHS capacity have meant that fewer people can access trials for non-COVID-19 related treatments. UK patient enrolment into clinical trials was 15% lower in June 2021 than in June 2019.²⁶ Recruitment was suspended for three out of four of Blood Cancer UK's funded advanced clinical trials.²⁷ In its evidence to this inquiry, the BSH noted that patients are increasingly having to travel long distances to access trials which most haematologists would consider to be "standard of care".

This is worrying because access to clinical trials can offer people early access to treatments that could prolong their survival or improve their quality of life. Clinical trials are also an important source of NHS income – the ABPI estimates that during the pandemic NHS Trusts had a deficit in income from commercial research of up to £447 million.²⁸

Recommendations

1. NHS England should commit to retaining beneficial service changes, as identified by the blood cancer community. These include access to newer medicines, community testing and the flexibility to access care in-person or remotely. However, there should not be a "one size fits all" approach.
2. NHS England should conduct an urgent evaluation of patient outcomes for those blood cancer and stem cell transplant patients whose treatment was paused or changed during the pandemic, to understand whether any of these changes may have led to disease progression or poorer outcomes. This analysis should be used to inform pathway development in anticipation of future peaks or pandemics.

²⁵ Evidence submitted to the joint inquiry by Penny Bibby, July 2021

²⁶ ABPI, *Clinical research in the UK: an opportunity for growth*, September 2021 <https://www.abpi.org.uk/r-d-manufacturing/clinical-research/clinical-research-in-the-uk-an-opportunity-for-growth/>

²⁷ Evidence submitted to the joint inquiry by Blood Cancer UK, August 2021

²⁸ ABPI, *Clinical research in the UK: an opportunity for growth*, September 2021 <https://www.abpi.org.uk/r-d-manufacturing/clinical-research/clinical-research-in-the-uk-an-opportunity-for-growth/>

3. All blood cancer and stem cell transplant patients, regardless of how and where they access care, or the stage of their pathway, should have a named CNS and be offered access to formal haematology-specific psychological support, where a need is identified.
4. NHS England should provide guidance on visitation policy which advises Trusts on appropriate safeguards, and with specific direction on end-of-life family visits, including using COVID-19 testing to allow visits. This should be developed in consultation with patients, carers, and their representatives. No one should die alone.
5. We recommend that, as part of the implementation of the Clinical Research Delivery Framework, the Government should provide regular reporting on the number of clinical trials underway in the NHS – by condition, phase, and location, benchmarked to pre-pandemic levels. This information should be provided to all NHS Trusts and the blood cancer community to enable greater awareness of and access to trial participation.



The blood cancer workforce

The blood cancer workforce is essential for delivering high-quality care, and this need is heightened by the distinct, ongoing vulnerability to COVID-19 of the blood cancer community.

Understaffing has been a longstanding issue in blood cancer services. In 2019 the British Society of Haematology (BSH) reported significant vacancies and insufficient numbers of traineeships to fill the growing demand for haematology professionals.²⁹

The pandemic has heightened this pressure; a third of the blood cancer professionals surveyed by the Blood Cancer Alliance (BCA) in July 2021 stated there are major staffing shortfalls, with a further 40% stating there are minor shortfalls.³⁰ In addition, three-quarters of respondents to a BSH survey conducted in October 2020, felt that stress and stressful work environments are increasing.³¹

“The biggest challenge is workforce. Covid has had a significant psychological impact on staff, and it is more difficult than previously to recruit and retain staff. Staff are also having to provide cover for those who are isolating due to Covid-related issues. The funding constraints imposed by NHSE have meant that it is more difficult to backfill posts which is putting increased pressure on teams.”

– British Society of Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT)

Due to the high demand for staff in intensive care units during the peaks of the pandemic, the NHS adopted a policy of “re-deployment”

of hospital doctors and nurses to cover these gaps. Although highly specialised services such as stem cell transplantation were protected from re-deployment to an extent, the high numbers of staff absences due to staff having to isolate, or care for family members isolating during the pandemic, has created persistent staffing shortfalls.

Professional bodies submitting evidence to our inquiry reported difficulty in retaining and recruiting new staff, due to the enormous pressures that staff are working under, and a lack of funding to backfill posts. This is also impacting patient experience, with many people having less time with their doctors and nurses at a time when their need for advice and guidance has never been greater.

Recommendations

1. NHS England should ringfence haemato-oncology staff, including haematology nurses, from re-deployment to other parts of the NHS. It is vital that haematology capacity is protected due to the severe vulnerability and complex support needs of people with blood cancer.
2. The long-term NHS People Plan should set out how the NHS will recruit and train haematology consultants, nurses, psychologists, pathologists, and other essential roles, with annual targets for additional capacity.
3. The mental health and wellbeing of the cancer workforce should remain a priority. An evidence-based staff mental health improvement plan should be developed and implemented to meet additional needs caused by the pandemic. This should be developed in consultation with management and staff and should be routinely reviewed.

²⁹ Evidence submitted to the joint inquiry by the British Society for Haematology, July 2021

³⁰ Evidence submitted to the joint inquiry by the Blood Cancer Alliance, August 2021

³¹ British Society for Haematology, membership survey, November 2020 <https://b-s-h.org.uk/membership/membership-survey-2020/z>

Appendix 1: Terms of Reference

One of the groups greatest struck by the COVID-19 pandemic is people with blood cancer. Having blood cancer is a similar risk to being over 80, and vaccines are much less likely to be effective, meaning that the blood cancer community has been shielding for over a year, to their great physical and psychological detriment. It has also impacted blood cancer treatment, emotional support, and diagnosis itself. The long-term impact of this crisis on the blood cancer community, therefore, is yet to be uncovered.

The APPG on Blood Cancer and the APPG on Stem Cell Transplantation and Cellular Therapies are holding a joint inquiry, looking into what is required for blood cancer services to be able to recover from the issues that have been caused or exacerbated by COVID-19.

Given that health and, within that, COVID-19 policies are devolved, the inquiry's scope can only consider blood cancer services in England. Although this inquiry will be blood cancer-specific, it will consider evidence about the impact of COVID-19 on cancer services more generally, in order to understand the wider context and how blood cancer relates to this.

This inquiry will accept evidence from all relevant parties, including clinicians, researchers, NHS, Government, patient organisations and professional bodies. The perspectives of people directly affected by blood cancer will also be used to inform this inquiry.

Questions for written evidence submissions:

1. What has the effect of the pandemic been on rates of diagnosis, length of waiting times, and types of treatment for blood cancer?
2. How can NHS England ensure that people with blood cancer, diagnosed before or during the COVID-19 pandemic, receive high-quality care and treatment?
3. How can we address the decline in referral rates created by the pandemic, and further build upon pre-COVID-19 rates of early diagnoses? Are there potential improvements that could make the process more efficient?
4. What will the long-term outcome (physical and psychological) be for people with blood cancer whose care was delayed or changed due to COVID-19?
5. How can we best enable patient access to specialised therapies (such as stem cell transplants) alongside post-COVID recovery?
6. What effect will COVID-19 and the efficacy of the vaccines for people with blood cancer have on their treatment and their outcomes. What measures are needed to ensure that treatment can be received safely while COVID-19 is still in circulation?
7. Is there a sufficient and adequately equipped workforce in place to ensure all of the above?

Appendix 2: Methodology

The inquiry received written evidence submissions and held two oral evidence sessions. The inquiry was also informed by desk research carried out by the APPGs' secretariats, Anthony Nolan and Blood Cancer UK. The information received across these channels has informed this report and its recommendations.

With COVID-19 developments taking place at such a fast pace, quantitative evidence relating to the impact of the pandemic on blood cancer services is often in provisional form (for example, NHS waiting time data) or unavailable. As such, many of our recommendations are based on the first-hand testimony and written submissions we received from people living with blood cancer, their families and healthcare professionals.

Acknowledgements

The inquiry received written submissions and heard oral evidence from nearly 70 individuals and organisations, including people living with blood cancer, their carers and families, healthcare professionals, patient organisations and charities.

Oral evidence session witnesses:

- Penny Bibby, patient advocate
- Prof Adrian Bloor, Consultant Haematologist and Honorary Clinical Professor, University of Manchester
- Henny Braund, Chief Executive, Anthony Nolan
- Rosie Dill, patient advocate
- Prof Adele Fielding, Professor of Haematology, UCL, and President of British Society for Haematology
- Alison Paterson, Haemato-Oncology Clinical Nurse Specialist
- Gemma Peters, Chief Executive, Blood Cancer UK

Written submissions:

- AbbVie
- Anthony Nolan Policy Insights Panel
- Blood Cancer Alliance
- Bristol Myers Squibb
- British Society for Haematology
- British Society of Blood and Marrow Transplantation and Cellular Therapy

- Cancer Research UK
- Janssen
- Myeloma UK
- Barry Neville, patient advocate
- NHS Blood and Transplant
- NHS Cancer Care Programme
- UK Myeloma Forum

The APPGs on Blood Cancer and Stem Cell Transplantation and Advanced Cellular Therapies would like to thank everyone who provided evidence and shared their story.