

Blood Cancer Alliance Response to the APPG Inquiry into the impact of COVID-19 on blood cancer services

The Blood Cancer Alliance (BCA) is a group of 15 charities that represent blood cancer patients across the UK. In the UK, around 40,000 people are diagnosed with, and 14,000 people lose their lives to, blood cancer every year. This makes it the 5th most common cancer and 3rd biggest cancer killer.

In preparation for drafting its response to this inquiry, the BCA initiated a survey for healthcare professionals to detail their experiences of the coronavirus pandemic on blood cancer patients.¹ 61 healthcare professionals from a range of medicals background and from a variety of regions across England responded to this survey between 17th June and 20th July 2021. These findings have helped to inform this response from the BCA.

1. What has the effect of the pandemic been on rates of diagnosis, length of waiting times, and types of treatment for blood cancer?

The coronavirus pandemic has exacerbated existing issues within the UK's healthcare system. Prior to the pandemic, the UK already faced significant challenges in diagnostic capacity, workforce, and infrastructure, all of which are necessary to provide patients with high-quality, personalised care. Of the healthcare professionals who responded to the survey, over half (53%) believe that blood cancer referral rates have decreased since the beginning of the pandemic, with nearly two-thirds (64%) now expecting to foresee a significant increase in referral rates over the next 6-12 months.

Reduced numbers of referrals inevitably lead to more people being diagnosed later, and in emergency care settings when their health has deteriorated, which we know results in poorer survival rates. 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.² Over a third of the healthcare professionals surveyed also suggested that their contact with patients had decreased during the pandemic.

Through necessity, the coronavirus pandemic has also accelerated rapid change and innovation across the healthcare system demonstrated in the adoption of online consultations, greater flexibility in the management of cancer, and additional treatment options. Half of the healthcare professional respondents (51%) indicated that there had quite frequently been instances where the treatment provided had been different to the treatment that would have been provided prior to the pandemic, with a further two-fifths (40%) revealing that this had happened occasionally.

There was a mixed response as to whether these new measures and techniques will be beneficial with only a fifth (21%) believing changes to treatments will have a positive impact, with a third (33%) stating they will have a negative impact. Of the positive new measures, clinicians identified the expansion of new treatments. A couple of respondents, however, did indicate that it is hard to quantify at this stage and that there is need for clarity in certain areas such as in block contracting. Of the reasons for the changes in treatment, over four-fifths (85%) identified COVID as one of the three main factors for treatment changes during the pandemic. Nearly half (49%) identified patient issues as one of the three main factors, with over a third identifying reductions in routine activities of cancer services (36%) and a lack of resources (34%).

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?

It is concerning that according to recent research from Blood Cancer UK blood cancer patients are accounting for a high proportion of COVID-19 admissions in intensive care.³ To help rectify this problem, we need inpatient data to develop an action plan to protect these patients who are not protected by vaccines.

¹ <https://www.surveymonkey.co.uk/r/6JJJFPV>

² <https://bloodcancer.org.uk/news/over-quarter-blood-cancer-cases-only-diagnosed-after-emergency-admission/#:~:text=Just%2040%25%20of%20people%20with,risk%20of%20serious%20side%20effects>

³ <https://bloodcancer.org.uk/news/80-of-people-with-blood-cancer-have-not-been-told-vaccines-may-not-work-for-them/>

As a matter of priority, sufficient focus must be given to diagnosing conditions that are rarer and more difficult to identify, alongside ensuring there are treatment pathways available. NHS England (NHSE) should urgently undertake an evaluation of whether GPs are making full use of NICE guidance on referral and recognition of suspected cancers. Analysis from parliamentary answers from the last year indicate neither NHSE nor DHSC has undertaken detailed analysis of to what extent the guidance is being followed.

An overwhelming proportion of the healthcare professional respondents (85%) believe that more should be done to protect blood cancer patients during their treatment or care to account for the uncertainty of vaccine efficacy amongst this group. The same percentage of healthcare professionals also suggested that they considered it part of their role to inform blood cancer patients about any changes to their treatment. It is also vital that national treatment guidelines are provided for this specific disease to plan and protect patients left unprotected.

Likewise, NHSE should allocate and prioritise specific resource for one or more of the Cancer Alliances to pilot self-referral to Rapid Diagnostic Centres (RDCs) to build the evidence base on its efficacy and resource impact as soon as possible. As previously highlighted, the coronavirus pandemic has caused rapid change and innovation across the healthcare system. The efficacy of these measures should continue to be reviewed and retained if beneficial.

Other suggested policy changes from the healthcare professionals who engaged with the survey include the Government setting a plan and promoting a whole-system approach to blood cancer recovery (22%); sustained investment in the blood cancer workforce, resources, technology and infrastructure (46%); proactive mental health support services to be made available for all patients (12%); collaboration between services to provide holistic care (20%).

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 which could make the process more efficient?

The coronavirus pandemic has made it essential for the healthcare sector to innovate. This is very much the case in the blood sector space with new treatment pathways available for blood cancer patients. These innovations have the potential to help address the decline in referral rates and improve patient care. Of the changes implemented since the beginning of the pandemic:

- a third of the surveyed healthcare professionals (35%) would like to see digitalised communications and care where appropriate,
- nearly two-fifths (38%) want to see innovation in medicine distribution and home administration of treatments, and
- over a quarter (26%) are keen to see access to a wider range of treatment options for people.

There were also demands for the more flexible therapy options to continue and the reactivation of face-to-face communication and treatment where possible.

In addition to these reforms, more investment in cancer services is necessary to match the ever-growing demand and ensure all patients have equitable access to early diagnosis, thorough investigations, and effective treatments. The ending of the Cancer Services Recovery Plan and Taskforce in March 2021 has unfortunately created a gap which now needs to be filled. Reforms also need to develop beyond the Long-Term Plan to address the backlog itself with greater focus on blood cancer which has consistently low two-week wait referrals and the highest number of GP appointments needed before referral of any common cancer.

Specifically for blood cancers, the current system is not set up to deliver improvements in early diagnosis. Flagship policies such as the roll-out of diagnostic hubs and RDCs must be properly resourced to make progress in diagnosing blood cancers faster. Such improvements will be critical to addressing the backlog.

NHSE should also work with GPs to ensure they recognise blood cancer symptoms, emphasising the use of routine blood tests, for example, to rule-out myeloma and repeat appointments to avoid delayed

lymphoma diagnoses. At a governmental level, we are strongly of the view that there is a necessity for the appointment of a designated clinical lead in Government for people who are clinically vulnerable to COVID-19 and the development of a cross-governmental strategy for supporting people who are clinically extremely vulnerable. At a practical level it is imperative that NHSE urgently undertake an evaluation to ensure GPs are making full use of NICE guidance on referral and recognition of suspected cancers.

The Government must also provide more investment in cancer services to match the ever-growing demand and ensure all patients have equitable access to early diagnosis, thorough investigations, and effective treatments. Specifically blood cancer should be included in the £20 million Elective Care Recovery Fund. Cancer treatment safe settings, such as hubs, should also be equipped to provide all cancer treatments necessary for the relevant health population.

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?

As previously discussed, the pandemic has exacerbated existing issues for people with blood cancer. A survey of people living with blood cancer, undertaken between March and July 2020 by Blood Cancer UK, found that 47% of respondents reported their blood cancer appointments and treatment had been impacted by the pandemic.⁴ Patients have had appointments cancelled or delayed, face-to-face consultations swapped to a telephone conversation, treatment altered such as their blood tests postponed, a pause or early termination to chemotherapy, or missing out on a stem cell transplant.

Delays in diagnosis lead to extreme stress and anxiety among patients; a position also highlighted by healthcare professionals who responded to the survey. A recent survey developed by Anthony Nolan revealed nearly three quarters of patients (74%) having worse mental health and wellbeing than before the pandemic with anxiety and frustration in particular highlighted.⁵ Blood Cancer UK's survey showed similar results, with 87% of respondents stating their mental health was impacted by the pandemic, with 67% saying the pandemic made them feel anxious. Patients have also reported difficulties in accessing mental health treatment with a large proportion (65%) experiencing delays.⁶ Dedicated financial support was recommended as a possible solution by healthcare professionals to the current strains blood cancer patients are facing in terms of employment and isolation, helping to ease the anxiety many blood cancer patients face in the current challenging environment.

Anecdotally, the BCA has also heard from medical professionals who stress that the increased levels and intensity of demand for services, as a result of the need to address the pandemic backlog, means resources will continue to be incredibly stretched, with resultant impacts for patients.

These professionals also identified longer term concerns arising from delayed treatments such as more limited later treatment options, later referrals and longer treatment; all of which result in poorer referral rates. A number of these professionals also expressed concern about facing a back log of referrals and whether there was the requisite number of staff to deal with the backlog. Other potential problems discussed included the possible reluctance of patients to return to hospitals, the need to balance consultations and the long-term impact on staff working in the sector.

5. How can we best enable patient access to specialised therapies (such as stem cell transplants) alongside post-COVID recovery?

Cancer treatment safe settings, such as hubs, should be equipped to provide all cancer treatments necessary for the relevant health population, and not focus on cancer surgery alone. Ongoing communication with patients by BCA member organisations has suggested widescale disruption to the provision of stem cell transplants during the first and subsequent peaks of the pandemic, resulting in delays. There remains an ongoing backlog in the provision of autologous stem cell transplants primarily

⁴ https://media.bloodcancer.org.uk/documents/Blood_Cancer_UKs_Covid-19-Survey-Report-February-2021.pdf

⁵ <https://www.anthonynolan.org/what-we-do/influencing-change/raising-awareness-blood-cancer-and-stem-cell-transplants/stop>

⁶ <https://www.anthonynolan.org/what-we-do/influencing-change/raising-awareness-blood-cancer-and-stem-cell-transplants/stop>

used in the treatment of cancers such as multiple myeloma. As stem cell transplants are usually only offered for relapsed or progressing haematological cancers where other treatments have been ineffective the risks of delayed access for patients can be severe.

Further resources should be provided to deliver the planning and infrastructure required to deliver complex interventions such as stem cell transplants in a COVID-19 secure manner. This includes investment into additional clinic space as well as equipment to deliver diagnostic services and treatments for blood cancer. Access to novel treatments and tests that can be administered in the community or in patients' own homes will help deliver benefits. Additionally, advances in delivering stem cell transplantation in an ambulatory setting will help with capacity.

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?

Research has shown that people with blood cancers are at higher risk of serious illness from COVID-19 both due to the nature of their disease and the treatments that they receive. Emerging evidence also suggests that vaccines are much less effective for this group.

We urgently need more investment in research to help us understand how effective vaccines are for this vulnerable patient group, as well as what treatment options there are. The current limited evidence is compounded by the consideration that the majority of blood cancers, are not included in the main government-funded studies, with a number of completed studies not publicly available. Only by fully understanding vaccine efficacy among the immunocompromised, will we see blood cancer patients feel confident in returning to hospital treatment.

25% of healthcare professionals who specifically provided suggestions on what measures are needed to ensure treatment can be received safely pointed to consistent antibody tests for patients to provide them with security and reassurance. There were also calls for continued social distancing in clinics and the use of facemasks and where possible early access to the vaccine booster to ensure that treatment can continue to be received safely for blood cancer patients during the pandemic. This is a highly prescient topic amongst blood cancer patients with 87% of healthcare professionals revealing that they had participated in conversations with patients about the efficacy of the vaccine.

In addition, there are a range of measures across government and in NHSE that need to be implemented. As previously highlighted, the BCA would like to see the appointment of a designated clinical lead for people who are clinically vulnerable to COVID-19 and the development of a cross-government strategy for supporting people who are immunocompromised. In addition to these measures, there is a need to communicate the ongoing risk to people who are immunocompromised and for clarity about the impact of the removal of legal requirements on masks and social distancing on the immunocompromised and for clear guidance to be provided for the immunocompromised. This will guarantee the requisite focus is being placed on this consideration in the highest levels of government.

7. Is there a sufficient and adequately equipped workforce in place to ensure all of the above?

Even prior to the pandemic there were longstanding concerns about staff shortages in the NHS and within the haematology sector. The pandemic has only served to increase these concerns. A third of the healthcare professionals (33%) surveyed stated there are major shortfalls with a further two fifths (40%) stating there are minor shortfalls in staffing. In the second oral evidence session conducted for this inquiry, Professor Adrian Bloor, Alison Paterson and Adele Fielding also expressed concern at the number of staff in the sector approaching retirement and whether these staff members could be replaced. Staff burnout and the possibility of staff having to isolate were also concerns raised by healthcare professionals.

This is married with the need for more investment in the haematology workforce, both in terms of growing the workforce and investing in staff wellbeing. Further resources should be provided to deliver the planning and infrastructure required to deliver complex interventions such as stem cell transplants in a COVID-19

secure manner. This includes investment into additional clinic space as well as equipment to deliver diagnostic services and treatments for blood cancer.

The coronavirus pandemic has also slowed the growth of RDCs. RDCs are an important development especially for less specific symptoms, such as weakness and fatigue, night sweats and weight loss, especially common with blood cancers. We are concerned that the infrastructure and workforce requirements to manage demand for blood cancer services and treatment are operating at maximum capacity and that this strained way of working has knock-on effects in terms of patient experience and the quality of care that patients can expect to receive.

List of Blood Cancer Alliance Members

African Caribbean Leukaemia Trust	Anthony Nolan	Blood Cancer UK
Chronic Lymphocytic Leukaemia Support	Chronic Myeloid Leukaemia Support Group	
DKMS	Leukaemia Care	Leukaemia and Lymphoma NI
Leukaemia Cancer Society	Leukaemia UK	Lymphoma Action
MDS UK	Myeloma UK	Race Against Blood Cancer
WMUK		

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www.bloodcanceralliance.org