

## **Blood Cancer Alliance Response to APPG for Radiotherapy, All-Party Parliamentary Group on Cancer and All-Party Parliamentary Group on Health Consultation: Solutions to the COVID induced cancer backlog**

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.

### **How large is the cancer backlog and what are the risks to patients?**

The coronavirus pandemic has exacerbated a pre-existing problem in regard to the cancer backlog. The health system is under even greater pressure, with increasing demands on cancer diagnostics and more urgent referrals. Official statistics reveal that between April and August 2020, GPs referred 6,335 people for tests for suspected blood cancer – which represents only 34% of the c. 18,400 people we would usually expect be diagnosed in the same period, based on recent data trends<sup>1</sup>.

Reduced numbers of referrals for testing will 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.<sup>2</sup> Delays in diagnosis also lead to extreme stress and anxiety among patients.

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.<sup>3</sup> Respondents described having 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.

For cancer patients awaiting a stem cell transplant or associated treatment, there is no straightforward method to measure the backlog as these patients are not monitored under national cancer waiting times. However, 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. However, anecdotal evidence, and data on the number of donor provisions by stem cell registries suggests allogeneic stem cell transplants have now resumed at pre-pandemic levels and there are very few patients waiting to receive a transplant because of disruption from the pandemic. However there remains an ongoing backlog in the provision of autologous stem cell transplants primarily 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.

### **Has the current response of Government and NHS leaders to the COVID induced cancer backlog been sufficient and is the current system equipped to tackle the crisis?**

The coronavirus pandemic has 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. The efficacy of these measures should continue to be reviewed and retained if beneficial.

The impact of the pandemic, married with pre-existing problems in cancer provision, has required charities to fill gaps in treatment and care, and we have seen a substantial increase in patient phone calls and messages to charity support teams. It can be argued that this has artificially eased the burden on the NHS - but is not a long-term solution.

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<sup>1</sup> <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>

<sup>2</sup> <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.>

<sup>3</sup> [https://media.bloodcancer.org.uk/documents/Blood\\_Cancer\\_UKs\\_Covid-19-Survey-Report-February-2021.pdf](https://media.bloodcancer.org.uk/documents/Blood_Cancer_UKs_Covid-19-Survey-Report-February-2021.pdf)

Even before the coronavirus pandemic exacerbated issues, we would argue that the UK's healthcare system faced significant challenges in diagnostic capacity, workforce, and infrastructure necessary to provide patients with the high-quality, personalised care needed to drive improvement. 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 rapid diagnostic centres must be properly resourced to make progress in diagnosing blood cancers faster. Such improvements will be critical to addressing the backlog.

### **What is needed to change?**

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 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 NHS or DHSC has undertaken detailed analysis of to what extent the guidance is being followed.

NHS England 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. More also needs to be done to change public perception that GPs are 'too busy' to see patients and efforts should be made to encourage patients with cancer symptoms to contact their GP.

### **Do we have the capacity within cancer diagnostics services, cancer treatments and the cancer workforce to deal with the COVID induced cancer backlog?**

The coronavirus pandemic has slowed the growth of RDCs. The RDC at Guys and St Thomas' hospital has witnessed a 31% fall in referrals. 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 also 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. The increased levels and intensity of demand as a result of the need to address the pandemic backlog means that these resources will continue to be incredibly stretched, with resultant impacts for patients.

### **Are current levels of funding enough to tackle the backlog?**

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.

### **What are the reforms, support and resources cancer services need to tackle the COVID induced cancer backlog?**

Reforms need to develop beyond the Long Term Plan (LTP) to address the backlog itself, and there needs to be 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: 30% of people diagnosed need three or more appointments.<sup>4</sup> NHSE's work to help GPs recognise blood cancer symptoms should emphasise the use of routine blood tests, for example, to rule-out myeloma and repeat appointments to avoid delayed lymphoma diagnoses.

NHSE needs to assess the impact of COVID-19 on changes to treatment and the implications this will have on future outcomes for patients. The ending of the Cancer Services Recovery Plan and Taskforce in March 2021 has also created a gap which now needs to be fulfilled.

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<sup>4</sup> <https://bloodcancer.org.uk/get-involved/support-our-campaigns/end-the-delays/#:-:text=NHS%20figures%20show%20that%20around,on%20people%20with%20blood%20cancer.>

Additionally, more investment is needed 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.

### **Are there any opportunities to tackle the cancer backlog being missed?**

The BCA believes that more needs to be done to change public perception that GPs are currently 'too busy'. This is particularly important for blood cancer patients, who often feel as their symptoms are not very specific or 'recognisable' as cancer, and do not wish to 'bother' their GP with them when they perceive their GP surgery to be stretched to its limits because of the pandemic.

Additionally, cancer treatment safe settings, such as hubs, should be equipped to provide all cancer treatments necessary for the relevant health population.

### **What technological or innovative solutions might be implemented long and short term to tackle the cancer crisis?**

The National Institute for Health and Care Excellence (NICE) has produced rapid guidelines, including the prioritisation of systemic anticancer treatments. We are conscious that NICE is currently undertaking a number of consultations on their methods and processes, but are concerned about the use of the word "curative" in the guidelines from NICE referring to prioritisation of patients for treatment making all non-curable cancers a lower priority by default. Some blood cancers such as Chronic Lymphocytic Leukaemia, for example, are chronic, incurable conditions, and patients suffering these conditions do not deserve to be lower priority when new life-extending treatments are considered.

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. The increase in the use of digital care during the pandemic has been positive for many patients but does risk further excluding some patient groups who may not have access to the necessary technology or have sufficient technological literacy.

### **What do cancer services need to look like in the future to improve survival of cancer patients?**

Blood cancer is different to solid tumour cancers in that there is no surgical treatment option, and patients are dependent on chemo and radio therapies, pharmaceutical treatment and stem cell transplantation. As previously discussed, 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.

### **What policy recommendations should the APPGs make to the Government for tackling the Covid-induced cancer crisis.**

As discussed in this response, the BCA would like to make the following recommendations:

- NHS England should urgently undertake an evaluation to ensure GPs are making full use of NICE guidance on referral and recognition of suspected cancers.
- Resources should be dedicated to change the public perception that GPs are currently 'too busy' to see patients and efforts should be made to encourage patients with cancer symptoms to contact their GP.
- The Government should 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.
- Cancer treatment safe settings, such as hubs, should be equipped to provide all cancer treatments necessary for the relevant health population.

### **Anything else you would like to say?**

We remain concerned about the lack of data relevant to blood cancers. The two-week wait pathway is the only data that has been used to quantify the backlog so far, but this is not the only route to diagnosis. Many blood cancers are diagnosed via A & E, or same day referral to GP, and there has been no data presented to say whether the number of people diagnosed via A & E has increased or decreased. To this end, there is a lack of certainty and clarity in terms of the impact of the pandemic on blood cancers, especially acute types. Notably, acute leukaemia already had the highest rate of emergency diagnosis of all cancers, and there are suggestions from patients we have engaged with this will have worsened with the pandemic, but there is not yet the data available to fully assess the extent of the problem.

#### **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
Race Against Blood Cancer		

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