

Blood Cancer Alliance Response to the Health and Social Care Select Committee Inquiry on 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.

1. Why do cancer outcomes in England – in particular survival – still lag behind comparable countries internationally?

Even before the coronavirus pandemic exacerbated issues, we would argue that the UK's healthcare system faced significant challenges in diagnostic capacity, workforce, and having the 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 need to be properly resourced to ensure progress in diagnosing blood cancers more efficiently and effectively. More investment in cancer services is also necessary to match the ever-growing demand and ensure all patients have equitable access to early diagnosis, thorough investigations, and effective treatments.

Comprehensive reviews of international evidence has also consistently revealed that key areas of cancer care are worse in England in comparison to other countries.¹ Data from EUROCARE-5, a large population based cancer registry in Europe, has outlined that for a range of blood cancers like non-Hodgkin Lymphoma and Acute Myeloid Leukaemia, the UK lags far behind the European average. For instance, the 5-year survival rate in England for non-Hodgkin Lymphoma stands at 79.1% compared to 86.3% in Finland.² There is strong evidence to suggest these disparities between England and the rest of the world are caused by a variety of key factors, namely delayed diagnosis with 30% of people with blood cancer needing three or more appointments before receiving a diagnosis, delays in accessing treatment and ongoing age bias with older patients being under-treated.³

2. How will covid-19 affect efforts to catch up to the best cancer outcomes internationally?

The coronavirus pandemic has intensified a pre-existing problem in regard to the cancer backlog and cancer outcomes. The health system is under even greater pressure, with increasing demands on cancer diagnostics and more urgent referrals. 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.

Treatment and appointments

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. A lack of blood sample tubes has also resulted in delayed blood tests which are vital for blood cancer patients. The impact of the pandemic, married with pre-existing problems in cancer provision, has then required charities to fill gaps in information, care and support. It can be argued that this has artificially eased the burden on the NHS but should not be interpreted as a long-term solution.

A recent survey of 6,417 blood cancer patients conducted by Blood Cancer UK discovered 47% of respondents have had their blood cancer appointments and treatment impacted in some manner by the pandemic.⁴ There is further evidence that this number could be significantly higher with many respondents

¹ <https://news.cancerresearchuk.org/2019/09/11/measuring-up-how-does-the-uk-compare-internationally-on-cancer-survival/>

² De Angelis R, Sant M, Coleman MP, et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE-5 - a population-based study. *Lancet Oncol* 2014;15:23-34

³ https://media.bloodcancer.org.uk/documents/bloodwise-delayed-diagnosis-report_RIQgdp7.pdf

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

to the survey reporting that their appointment had not yet been scheduled.⁵ Respondents to this survey also reported having their treatment altered such as the postponement of blood cancer tests, pausing or early termination to chemotherapy, or missing out on a stem cell transplant. These findings are supported by research from Leukaemia Care demonstrating that the main issues for patients since the origin of the pandemic have been access to holistic care services, non-curative treatments, and changes to the way hospitals operated. These issues have yet to be fully investigated and tackled.

Specific treatments have also been impacted during the pandemic. In a survey conducted by Leukaemia Care in January 2021, 17.4% of Chronic Lymphocytic Leukaemia (CLL) patients who had received intravenous immunoglobulins (IVIG) before the pandemic, disclosed that they had stopped receiving the treatment and 13% said their access to this treatment had stopped for a period of time as a result of the pandemic but had now resumed.⁶ Moreover, for people diagnosed with a leukaemia that is not Acute Myeloid Lymphoma or Chronic Lymphocytic Leukaemia, the rate of people presenting as an emergency has increased from 41.9% in the last quarter of 2019 to 46.3% in quarter 3 of 2020.⁷ This method of diagnosis has been associated with decreased survival at both 3 months and 1 year compared with other routes to diagnosis. In terms of physical long-term outcomes, prognosis will also likely be worse for those patients who presented later and were diagnosed later, which will have a negative knock-on effect.

Clinical trials

The pandemic has also led to the pausing of many clinical trials meaning more limited treatment options for blood cancer patients. Trials did restart after the slowing of the first surge of the pandemic but slowed down again when COVID-19 infections and demands on resources increased. This is likely to have been repeated in the recent third spike of infections seen in the UK. There was and is also reduced ability for patients to travel for clinical trials due to restrictions on essential travel and/or confusion over the rules.

The coronavirus pandemic has slowed the growth of Rapid Diagnostic Centres (RDCs). The RDC at Guys and St Thomas' hospital has witnessed a 31% fall in referrals.⁸ RDCs are an important development especially for less specific symptoms, such as weakness and fatigue, night sweats and weight loss, particularly 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 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.

Psychological impact

The additional psychological strain on patients who were not allowed to see loved ones from diagnosis to treatment due to the pandemic is now also becoming clear. Conversations between charities and patients have revealed that more psychological support was needed both during and after treatment, due to the additional toll the pandemic restrictions had on patients' mental health.

Data

We also 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,

⁵ https://media.bloodcancer.org.uk/documents/Blood_Cancer_UKs_Covid-19-Survey-Report-February-2021.pdf

⁶ <https://www.leukaemiacare.org.uk/support-and-information/latest-from-leukaemia-care/blog/leukaemia-cares-submission-to-the-recent-appg-inquiry/>

⁷ <https://www.gov.uk/government/collections/emergency-presentations-of-cancer>

⁸ https://media.bloodcancer.org.uk/documents/Blood_Cancer_UKs_Rapid_Diagnostic_Centre_report_-_February_2021.pdf

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 that, this will have worsened with the pandemic, but there is not yet the data available to fully assess the extent of the problem.

Innovation

However, the coronavirus pandemic has also seen rapid change and innovation across the healthcare system such as the adoption of online consultations, greater flexibility in the management of cancer, and additional treatment options. Furthermore, access to novel treatments and tests that can be administered in the community or in patients' own homes will help deliver benefits and should be maintained. NHSE has published treatment options during COVID-19 to allow for greater flexibility in the management of cancer. The efficacy of these measures should be reviewed and retained if beneficial. 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.

3. Will implementing the Long Term Plan for cancer improve cancer outcomes to the level of the best countries internationally?

While implementing the Long Term Plan will make a positive difference, there are still many aspects of the plan which are of concern to blood cancer patients. The ambitions around diagnosis in the Long Term Plan on staging is unlikely to capture progress in many blood cancers with alternative data, like routes to diagnosis, not published quick enough to know if progress is being made. This is underlined by the current lag on data on the NCRAS website which stands at 4 to 5 years.

Furthermore, whilst the desire for all patients to have a Clinical Nurse Specialist is admirable, this is unlikely to be achievable without significant workforce changes. Going forward, sufficient focus must also be given to diagnosing conditions that are rarer and more difficult to identify and also ensuring that there are treatment pathways available. We are anxious that the Long Term Plan does not include a sufficient enough focus on blood cancers which consistently have low two week wait referrals and the highest number of GP appointments needed before referral of any common cancer.

It is also disappointing that the Cancer Services Recovery Plan and Taskforce ended in March 2021, which was helping to cover the gaps in the Long-Term Plan. In order to improve outcomes, 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. In particular, RDCs are an important development especially for vague symptoms. The NHS needs to prioritise its roll out across all cancer alliances as we try to get more people through the system.

To rectify these problems, NHS England (NHSE) must also urgently undertake an evaluation to ensure GPs are making full use of NICE guidance on referral and recognition of suspected cancers. Parliamentary answers last year showed that neither NHS or DHSC has undertaken any detailed analysis of to what extent the guidance is being followed. This needs to change. Going forward, NHSE's work to help GPs recognise blood cancer symptoms should particularly emphasise the use of routine blood tests to rule-out myeloma and repeat appointments to avoid delayed lymphoma diagnoses. Moreover, the ability for patients to self-refer could be an important measure in reducing diagnosis times. NHS England should allocate specific resources for one or more cancer alliances to pilot self-referral to RDCs in order to build the evidence base on its efficacy and resource impact as soon as possible.

We also have existing concerns about produced rapid guidelines, including the prioritisation of systemic anticancer treatments produced by The National Institute for Health and Care Excellence (NICE). We are conscious that NICE is currently undertaking a number of consultations on their methods and processes but are worried 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.

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