Blood Cancer Alliance Response to Health and Social Care Select Committee Inquiry Call for Evidence: Delivering core NHS and care services during the pandemic and beyond.

The Blood Cancer Alliance (BCA) is a group of 14 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.

Section 1: The impact of COVID-19 on blood cancer services and care

Many of the observations below are based on anecdotal evidence supplied by the patients we represent, and clinicians we work with. The issues we raise are of grave concern to BCA members and the patients we represent.

Delay to treatment

- It is clear that many blood cancer patients have been informed their treatment will be postponed due for reasons related to COVID-19. We do not yet have numbers, but our anecdotal evidence suggests this is a very significant proportion of patients, and includes patients across all blood cancer types, and across the full spectrum of treatment options, including chemo and radiotherapies, pharmaceutical treatment and stem cell transplantation. To be clear, these patients would otherwise currently be receiving treatment for their condition.
- What is less clear at present is the reason for postponement, how long delays to treatment may be, and how the NHS will track these delays. We understand that in many cases treatment is postponed as immune-compromised blood cancer patients are at significant risk of contracting COVID-19 if they enter a hospital setting for treatment, and that risk currently outweighs the risk of treatment delay – although the latter risk is not insignificant. While this is an appropriate risk-assessment exercise in the short term due to blood cancer patients' acute vulnerability to COVID-19, there is an urgent need for a solution. Establishing safe settings in which critical blood cancer treatment can be administered should be an urgent priority within the NHS.
- Delays to treatment often impact blood cancer patient outcomes. We also know from our patients that extreme stress and anxiety is being caused by treatment delay and by the lack of clear information on length of delay. It is quite simple devastating for patients and families. We therefore stress again the need for urgent prioritisation of establishing safe settings for blood cancer patients to receive treatment within the NHS.
- There is also a need for clear communication with patients regarding their treatment delay, and in particular the duration of the delay, to ensure they remain informed and reassured where possible.
- Moreover, the NHS must ensure no patient falls through the cracks during treatment delay. Blood cancer patients' conditions can deteriorate rapidly. The assessment of whether risk of COVID-19 infection is higher than risk of treatment delay may change based on such deterioration. It may then be appropriate to begin treatment regardless of COVID-19 risk. When treatment is delayed it is unclear at present how often patients will be monitored for this decline, with the burden potentially falling to the patient to self-report changes in their condition. The NHS should ensure patients subject to delay are tracked, regularly monitored and risk assessment of treatment reviewed.
- The delay to treatment may cause a backlog among blood cancer patients for each specific type of treatment. It is unclear how patients will be prioritised when treatment becomes more widely available again, when this backlog inevitably causes demand that exceeds NHS capacity.
- We understand that efforts to establish safe 'cancer treatment hubs' has begun. We welcome progress in this area. However, it also appears that localised hubs may not provide services for all types of cancer and

may be focused on cancer surgery alone in some cases. This is extremely worrying and has the potential to create a postcode lottery for cancer patients across the UK. Blood cancer is different to solid tumour cancers in that no surgical treatment option, and patients are dependent on chemo and radio therapies, pharmaceutical treatment and stem cell transplantation. If cancer hubs focus on surgical treatments alone then this policy will completely fail blood cancer patients. Cancer treatment safe settings, such as hubs, should be equipped to provide all cancer treatments necessary for the relevant health population.

Diagnosis of blood cancer

- Evidence gathered by Cancer Research UK suggests that referrals for diagnostic tests for cancer have dropped by 75% since the beginning of the pandemic. Delays to diagnosis lead to restricted treatment options and poorer outcomes across all cancers.

- Blood cancer is one of the most prevalent cancers to be diagnosed in the emergency setting – a significant indicator of late diagnosis, with an impact on patient outcomes, in terms of both reduced survival and worse patient experience. We expect there to be a significant impact on early diagnosis of blood cancers in coming months caused by public perception that access to their primary care services is limited. More needs to be done to change 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.

Impact on ongoing cancer treatment

- It is clear that COVID-19 will have a long-term impact on how care is delivered across the NHS. As such, there is a need to find solutions for how COVID-19 and blood cancer care can be integrated, including measures to prioritise COVID-19 testing for the most vulnerable blood cancer patients and increasing community support.

- COVID-19 is not just having an impact on treatment, but also is disrupting long-term follow-up blood cancer care, which is vital to improving quality of life for blood cancer patients. The impact of COVID-19 should be assessed across the whole blood cancer pathway, from diagnosis to survivorship care.

- The National Institute for Health and Care Excellence have produced rapid guidelines, including the prioritisation of systemic anticancer treatments. We are concerned about the use of the word "curative" in the guidelines from NICE referring to prioritisation of patients for treatment. The use of this word makes all non-curable cancers a lower priority by default. However, treatment for incurable cancers, such as chronic lymphocytic leukaemia, is still highly effective. If the current guidance is not rephrased then all those living with incurable cancers may struggle to access treatment.

Government support for blood cancer patients

- Stress, and potential hardship has been caused to blood cancer patients due to the length of time it has taken for them to be identified as vulnerable by the NHS. A significant proportion of blood cancer patients had still not received notification from NHS England of their vulnerable status six weeks after measures were announced, and therefore were unable to access support while shielding from local and national government and supermarkets. Furthermore, delay in letters has left blood cancer patients unable to explain their position when requesting furlough from employers.

- Patients have informed us that they feel shielding advice from Government has also been unclear, both in as it applies to them, and as it applies to those they live with.

Section Two: Suggested questions for the HSCSC

1. Why is blood cancer treatment being delayed within the NHS and what urgent steps are being taken to address challenges in providing blood cancer treatment?

2. Why is work to establish new, safe cancer treatment hubs prioritising particular cancers and focused solely on surgery, and what is being done to ensure all cancer patients can access life-saving treatment in a safe environment regardless of where they live or what cancer treatment they need?
3. What is NHS England doing to monitor and track patients whose treatment has been delayed? And how will NHS England ensure patients are reviewed regularly to ensure the delay is still appropriate?
4. What is being done to address the fall in diagnostic referrals for cancer?
5. Will NICE change the COVID-19 rapid guideline: delivery of systemic anticancer treatments to remove the references to 'curative' and ensure that those with chronic, incurable blood cancers can access treatment that can improve quality of life and extend life by a significant number of years?
6. Why has it taken so long for the NHS England to identify blood cancer patients as vulnerable, and what assessment has been made of the impact of this delay on the physical and mental well-being of these patients? And what steps are being taken to protect those vulnerable patients who have still not received letters from NHS England?
7. What steps is NHS England taking to ensure that blood cancer patients have access to clear and consistent shielding advice? And how is this being aligned with the Coronavirus Job Retention Scheme to ensure that those shielding (and those who live with them and cannot socially distance) are being furloughed by their employers?

Section Three: List of Blood Cancer Alliance Members

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

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