

Written evidence submitted by Blood Cancer Alliance (ECS0011)

INTRODUCTION

The Blood Cancer Alliance is a group of fifteen UK charities. Together, we are working to tackle the issues blood cancer patients face, and improve the experience and outcomes of all those living with blood cancer.

As a general point, we would like to raise that NHS England has not issued a formal report on progress against the Long Term Plan since December 2020. While this is understandable, given the impact of the pandemic, it leads to difficulty for patient organisations in making any assessment of progress against objectives within cancer.

In general, the Blood Cancer Alliance supports the commitments relating to cancer within the Long Term Plan. However, we are concerned about the lack of specific information as to how progress will be achieved within blood cancer. Blood cancers are often more complex than solid tumour cancers, and they require specific consideration as to how improvements in care and outcomes can be achieved, to reflect the wide variation in patient need and experience.

WORKFORCE

We do not believe the commitments in the Cancer Workforce Plan are being met in relation to haematology and haemato-oncology and nor will they be met without significant investment in the workforce, and robust long-term planning.

Challenges within the haematology workforce have been set out by the British Society of Haematologists in their 2019 Workforce Report. Issues identified are as follows:

- There are a reduced numbers of trainees to fill consultant haematologists post. The number of doctors being recruited to haematology training posts had fallen more than a third (36%) 2017-19
- Vacancies are likely to rise as current workforce approaches retirement. More than one in ten consultants are due to retire within the next few years, which could trigger a further decline in numbers
- Low morale, sickness and absences are affecting the haematology workforce, as they are across the NHS. Between October 2017 and October 2018, the average number of sick days per haematology department was 796 across staff including consultants, nurses and lab scientists.
- More than a quarter (27%) of those absences were taken by employees suffering from stress or mental illness. The workload burden is a likely factor in employees suffering physical and mental health problems.
- The rising number of complex treatments available requires more intensive long-term care that was not previously planned for. This has added additional pressure to services already under strain.

In this context, the Blood Cancer Alliance is urging the Government and NHS England should set out how the NHS will fund, recruit and train haematology consultants, nurses, psychologists, pathologists, and other essential roles, with annual targets for additional capacity.

In addition to this, 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

DIAGNOSTICS

COVID-19

The coronavirus pandemic has intensified a pre-existing problem with the cancer backlog and cancer outcomes, which were already poorer than comparably developed nations.¹ The pandemic has made reversing this trend even more challenging, and we are gravely concerned that the target to diagnose 75% of all cancers at earlier stages will not be met at current levels of activity.

The health system is under even greater pressure, with increasing demands on cancer diagnostics and record waiting times. The pandemic will result in more people being diagnosed at later stages when their health has deteriorated, which we know results in poorer patient experience and survival rates.

We have yet to see data from NHS England that will demonstrate the full impact of the pandemic on diagnosis within blood cancer. It is clear however that concerted and sufficiently resourced efforts are needed to mitigate the damaging effects of the pandemic.

Data

The Blood Cancer Alliance, however, remains concerned about the lack of available data specifically relevant to blood cancers to facilitate full analysis of whether improvements are being made. 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 that, this will have worsened with the pandemic, but there is not yet the data available to fully assess the extent of the problem. The Rapid Cancer Registration Dataset², for example, has only published data to March 2021 – and that data has only been available since September 2021. We believe more timely and transparent publication of data would be helpful to understand the challenges.

Improvements for service users

Early diagnosis is critical to increasing the chance of positive outcomes in cancer treatment. This is as true in blood cancer as it is in other cancers. However, blood cancer patients experience significantly worse delays to diagnosis than patients with breast, lung, colorectal and prostate cancers. It remains the case that 3 out of every 10 blood cancer (30%) cases in England are diagnosed after presenting to the NHS as an emergency – when their disease is likely to have progressed and they have significant health complications. This is compared with just 3% in breast cancer, 7% in prostate cancer, and 21% in colorectal cancer (Blood Cancer Dashboard data). The number of patients who had to see their GP five or more times before being referred for specialist treatment is double that of patients with other cancers in England (5% vs. 10% CPES 2019), and nearly double in each of the regions.

The Blood Cancer Alliance supports the roll out of Rapid Diagnostic Centres. Evidence from pilot RDC models in the UK, Wales and Denmark indicate that RDCs have the potential to diagnose blood

¹ <https://www.nuffieldtrust.org.uk/resource/cancer-survival-rates#background>

² [Rapid Cancer Registration Dataset](#)

cancers more quickly than via other routes. It has been estimated that around 10-15% of cancers diagnosed by RDCs will be blood cancers, most commonly lymphoma, myeloma and leukaemia. The evidence also shows that RDCs could significantly cut the time to diagnosis, and – although the available data is from a relatively small set of patients – evidence suggests RDCs could potentially diagnose more blood cancers at an early stage compared to normal diagnostic routes³.

That said, the Blood Cancer Alliance would welcome more specificity from the NHS as to how the challenges of diagnosis within blood cancer will be addressed. We also believe 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.

Impact on other services

In order for RDCs to effectively diagnose cancers it will be vital that they have access to specialist advice. For blood cancer diagnoses this will require access to a haematologist, either as part of the core clinical staff for the RDC, via a multidisciplinary team, or through direct liaison with the haematology department. Developing strong links into existing specialties will be fundamental to the effectiveness of RDCs given that there is no general internal medicine specialty in secondary care within the UK, and RDC clinical leads can be drawn from any relevant specialism.

NHS England, NHS Improvement and Health Education England (HEE) should ensure that the additional demands on haematology and other cancer specialties from RDCs are accounted for in the future Long Term Workforce Plan for the NHS. While this plan has been expected for some time, it has yet to be published.

Future ambition

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 nations 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.

LIVING WELL BEYOND CANCER

The Blood Cancer Alliance does not see evidence that the commitment for every patient to have a full personalised care plan, taking account of their short and longer term physical, emotional and holistic needs, has been met.

In stem cell transplantation – an established treatment for some blood cancers - for example, only 48% of transplant centres in the UK offer a full Late Effects Clinic to assist patients with the long term physical side effects of their treatment⁴. Moreover, within stem cell transplantation, the vast majority of transplant centres do not have readily available psychological support. To put this in context, over 80% of blood cancer patients surveyed by Blood Cancer UK in 2015 identified that they suffered from mental health issues after diagnosis.

Personalised care also needs to be age appropriate and satisfy the unique needs of 0-25 year olds - this should include their social, educational, emotional and financial needs.

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

⁴ <https://pubmed.ncbi.nlm.nih.gov/33082553/>

We are unclear as to how NHS England is monitoring and tracking progress in this area, or how, in the absence of established care pathways, clinical teams can have the confidence to provide, or signpost patients to, these services.

Ultimately, the realisation of this commitment cannot simply be a case of asking current cancer teams to do more with the same resource, and in many cases, less. Strong investment in services, and adequate staffing resources, is required to realise this commitment. NHS England must publish details of how it will address the challenges of resources and investment in this context.

INNOVATION AND TECHNOLOGY

The Blood Cancer Alliance welcomes the expansion in number of hospitals in England able to offer CAR-T therapies to patients. This is an important treatment for eligible blood cancer patients, and we would welcome further information from NHS England as to how specialist centres will be expanded to take account for the growing number of these kinds of therapies. In the absence of this kind of planning, our concern is the lack of capacity within the NHS to accommodate the needs of this growing patient population will not be addressed, and patients will be denied these treatments due to a lack of appropriate infrastructure. The same point can be made about the need to equip the NHS Workforce to deliver these treatments to a growing number of patients.

It is likely that we will see exponential growth in the number of advanced therapies being made available to UK cancer patients, and NHS England should develop a robust plan of how to scale up capacity in order to enable this to happen. Of significant importance will be to map current capacity against likely growth in requirement – both in terms of staff resource and training, but also in terms of hospital infrastructure.

The needs of these patients also must be assessed, and this can only be achieved if both outcomes and Quality of Life data is collected and published. NHS England must resource treatment centres to adequately collect data.

In general, however, LTP's commitment is not specific enough in terms of ensuring that UK patients have timely access to new and innovative therapies. While improving radiotherapy infrastructure is important, what is also of significant importance to blood cancer patients is ensuring the UK's medicines appraisal process is fit for purpose for the future, and able to accommodate novel therapies, including cell and gene therapies.

We support the continuation of funding of the Cancer Drugs Fund at the current level, and recognise this is an important mechanism for ensuring cancer patients can access new treatments. The CDF has historically been particularly important for access to blood cancer treatments, and the current list (as at 27 May 2020) includes over 20 blood cancer indications.⁵

We do, however, believe that the recent review of methods and processes for appraising innovative new treatments undertaken by NICE was a missed opportunity to improve the potential for patients with rarer cancers, including many blood cancers, to access innovative treatments. The NICE methods and processes consultation did not go far enough in addressing how uncertainties at time of appraisal, common in most appraisals for new treatments where patient numbers are small, such as blood cancers, can be taken into consideration. The CDF is not limitless in funding, and with a number of promising new therapies for rare cancers in the pipeline, it is not clear whether the resource in the CDF, nor the normal appraisal system will be adequate to ensure patients can access

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<https://static1.squarespace.com/static/5b98cdc612b13fdd2982129d/t/5f8d299049970b619a431007/1603086741943/BCA+report+Rapid+Access+to+New+Drugs+and+Treatments+for+people+with+Blood+Cancer+on+the+NHS.pdf>

them. The Blood Cancer Alliance called for a rarity modifier within the process, to mitigate against the risk of patients with rare blood cancers being disadvantaged, but this proposal was not adopted.

List of Blood Cancer Alliance Members

- Blood Cancer UK
- Leukaemia Care
- Anthony Nolan
- Leukaemia UK
- Lymphoma Action
- Myeloma UK
- Leukaemia and Lymphoma NI
- CLL Support
- CML Support
- African Caribbean Leukaemia Trust
- DKMS
- MDS UK
- Race Against Blood Cancer
- WMUK
- Leukaemia Cancer Society

February 2022