

NEW REPORT FINDS BLOOD CANCER PATIENTS BELIEVE THAT THE GOVERNMENT SHOULD DO MORE TO IMPROVE ACCESS TO NEW TREATMENTS.

The Blood Cancer Alliance launches a new report exploring access to blood cancer treatment at online parliamentary event hosted by Henry Smith MP

- New research commissioned by the Blood Cancer Alliance has found four fifths (88%) of blood cancer patients believe the Government should do more to make sure patients can access new treatments.
- The report illustrated that two thirds (67%) of blood cancer patients are concerned about accessing treatments that are in development in the future, with one in ten (11.5%) stating they are extremely concerned.
- The Alliance is also calling on the Department of Health and Social Care for reassurance that the change from the Cancer Drug Fund to the Innovative Medicine Fund will not disadvantage blood cancer patients from accessing treatments that would otherwise have been available before.
- The research also identified that there is an urgent need for patients to be more involved in research and development. The Alliance is calling on NICE to improve its use of patient perspectives as part of its decision-making process.

London, Monday 19th October -The Blood Cancer Alliance will today publish a new report identifying challenges blood cancer patients face in accessing new drugs and treatments on the NHS. The report is being launched at an online event hosted by the chair of the APPG on Blood Cancer, Henry Smith MP, with representatives from the pharmaceutical industry, parliament, patient representatives and health body representatives due to attend.

The findings in the report coincide with an ongoing review by NICE into the way drugs are assessed for use in the NHS. The patient survey illustrated more than four fifths of blood cancer patients believe the Government (88%) and the pharmaceutical industry (81%) should do more to ensure patients can access new treatments. The survey also showed that two thirds (67%) of blood cancer patients are concerned about accessing treatments that are in development in the future, and one in ten (11.5%) are extremely concerned.

The report identified ten key issues that need to be resolved to improve patient access to new treatments and includes nineteen further recommendations for a variety of stakeholders including Parliamentarians, the pharmaceutical industry, health body representatives and policy stakeholders.

A vital issue the report identified is that while the Cancer Drugs Fund has been particularly important for enabling access to blood cancer treatments, the Government's intention to change this to a broader Innovative Medicines Fund is causing concern for future access. The Alliance is calling on Health Secretary Matt Hancock MP to give reassurance that funding for the Innovative Medicines Fund will be sufficient so as not to disadvantage blood cancer patients from accessing treatments that would otherwise have been available through the Cancer Drugs Fund.

The report also found that blood cancer patients are not adequately represented in the process for appraising the effectiveness of new medicines and treatments. The Blood Cancer Alliance is calling for NICE and the pharmaceutical industry to review their appraisal process to include patients and their views.

Chair of the APPG on Blood Cancer, Henry Smith MP, added: *"Blood cancer treatments are more complex than solid tumour cancers. Surgery and radiotherapy are rarely an option. Blood cancer patients are instead reliant on pharmaceutical treatments such as chemotherapies and targeted therapies, combination treatments, or in some cases stem cell transplantation. Ensuring blood cancer*



patients have timely access to the best and most effective new medicines and treatments on the NHS is therefore critical to improving patient outcomes. The Cancer Drugs Fund has been instrumental in achieving this, and any change to it must not have a detrimental impact. It is vital that all stakeholders work collectively to better understand all the findings in the report and work together to develop the recommendations to ensure patients have the greatest possible outcome.”

Chair of The Blood Cancer Alliance, Zack Pemberton-Whiteley, commented: *“Improving outcomes for blood cancer patients - both in terms of disease survival and quality of life – is the ambition that drives the Blood Cancer Alliance. We commissioned this research report to strengthen our case as to how, by making positive policy changes with regard to new blood cancer treatments, the pharmaceutical industry, health body representatives, Government and wider blood cancer community can work collaboratively to secure better patient outcomes. The recommendations are focused on helping to improve outcomes in blood cancer whilst also very much putting patient interest and voice firmly back in the centre of the treatment appraisal process.”*

ENDS.

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About the Blood Cancer Alliance

The [Blood Cancer Alliance](#) is a group of fifteen charities who together are working to tackle the issues blood cancer patients face and improve the experience and outcomes of all those living with blood cancer. The Alliance has a UK-wide remit and is open to registered charities who have a strong primary focus on blood cancer. Our current members are:

ACLT, Anthony Nolan, Blood Cancer UK, CLL Support, CML Support Group, DKMS, Leukaemia Care, Leukaemia and Lymphoma NI, Leukaemia Cancer Society, Leukaemia UK, Lymphoma Action, MDS UK Patient Support Group, Myeloma UK, Race Against Blood Cancer and WMUK.

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About the Report

The Blood Cancer Alliance commissioned Leela Barham, an independent researcher, to undertake the research and write the report. The research in the report included a rapid evidence review, an environmental scan, one-to-one anonymised telephone interviews with seven experts during May and June 2020 and an online survey of patients and/or carers of those with blood cancer that was run from 17 June to 1 July 2020. Over 700 patients and carers responded. The Alliance wanted to take an evidence-based approach as well as learn from the real experiences of patient organisations who have participated in appraisals.

The ten findings in the report include:

1. New blood cancer treatments are coming through and HTA agencies and companies need to prepare for their appraisal.
2. It is vital to involve patients from R&D and beyond and for their involvement to have an impact.
3. Modifiers – additional factors that are not easily incorporated into approach to the clinical and economic evidence used in HTA - play a role in HTA but need revisiting.
4. The CDF has enabled access for blood cancer patients but a change to an Innovative Medicines Fund is causing concern for future access.
5. Uncertainties are a common feature in the evidence base for blood cancer treatments at the time of appraisal and real-world evidence could help.

6. The CDF has enabled access for blood cancer patients and enables the generation of further evidence when there are uncertainties at the time of first appraisal. However, within the CDF the evidence that NICE needs to counter uncertainty at the time of the first NICE appraisal is not always being collected.
7. Non-submissions are rising in blood cancer. Key drivers include the challenge of combination pricing and the lack of multi-indication pricing.
8. There is more potential for outcome-based payment where companies are rewarded on the basis of the outcomes that their treatments generate.
9. Submissions to NICE have errors; submissions need to improve
10. Speedy access requires speedy collaboration.