

The unmet needs of ethnic minority blood cancer patients

A summary of new research commissioned by the Blood Cancer Alliance

Background

In 2021 the Blood Cancer Alliance (BCA) initiated a project to better understand the experience of people from Black, Asian and minority ethnic backgrounds who have had a blood cancer diagnosis, and to identify the challenges and specific unmet needs they face throughout their care journey, from diagnosis to follow-up support. The project comprised of two pieces of commissioned research:

- A patient-focused study, undertaken by Clearview Research, which included a literature review, a patient survey and patient focus groups, to identify unmet needs.
- A review of cancer data sets, undertaken by the University of Hertfordshire, to understand differences in outcomes and experience of patients from ethnic minority backgrounds. The University of Hertfordshire research also included a survey of healthcare professionals working in blood cancer to understand their views on the underlying causes of unmet needs among patients from ethnic minority backgrounds.

A summary of the key research findings can be found below, and the full reports can be found at this [link](#).

Patient Insights: Key Findings

- The BCA engaged with 6 patients via focus groups and 22 patients via a survey. Patients from Black, Asian and ethnic minority backgrounds are four times more likely to have delays in referral for their blood cancer diagnosis. 45% of Clearview survey respondents reported having to visit their GP 3 or more times before referral for testing, and 20% reported having to visit their GP five or more times.
- Almost half of survey participants did not feel as though they were taken seriously when they explained their symptoms to the GP and some reported experiencing discrimination within their diagnosis journey. Over half of our survey participants felt their diagnosis could have been delivered in a more sensitive way.
- Participants did not feel as informed in decision-making about their care in comparison to National Cancer Patient Experience Survey (NCPES) data for the whole patient population (27% vs 3%). Patients reported being afraid to ask clinicians questions and seek information elsewhere. A key theme was lack of access to translators for those for whom English is not their first language, and how that can impact on how involved patients can be in decision-making. Patients also reporting feeling like they have no control over clinical trial treatment decisions, because of a lack of understanding regarding the information shared about the trial.
- The research identified that it is important to recognise and understand how diverse a patient's care and support needs can be, and that having access to a clinical expert, such as a Clinical Nurse Specialist (CNS), is useful and inclusive. However, only half (54%) of patients knew the name of a CNS and only three participants in the Clearview research project reported being offered access to psychological support services within their care journey.
- Less than a third of survey respondents (32%) reported being asked to be involved in clinical trials, and of that percentage, nearly half reported not understanding the information on trials that was presented to them.

Review of Cancer Data: Key Findings

- There is a lack of accurate, publicly available data on the prevalence of blood cancer by ethnicity. It is therefore difficult to know the true extent to which illness patterns vary by ethnicity, and how outcomes are impacted by the intersection of ethnicity and other patient socio-demographic characteristics.

- The available data does show that people who identify as Black British are 2-2.5 times more likely to be diagnosed with myeloma than people identifying with a White ethnic group, and that some blood cancers are more common among men from White and Black heritage backgrounds.
- Minority ethnic patients were under-represented in the 2019 NCPES according to 2018 prevalence data. However, responses to the NCPES highlight some key trends in responses that likely signal what matters most to patients from specific ethnic groups that could be explored further to drive quality improvement initiatives.
- The results for 2019 NCPES, question 61: “overall how would you rate your care?”- Asian respondents scored lowest on average (8.28 out of 10), those of Black heritage slightly higher (8.50 out of 10) and patients identifying with a White heritage the highest score (8.95 out of 10). Minority ethnic blood cancer patients also had lower scores relating to the quality of support and information they received.
- Interviews with HCPs identified that being able to provide personalised care that is culturally appropriate and takes account of ethnicity related inequalities is crucial. Other factors that influence patients accessing and understanding their care included health illiteracy and language barriers and clustering of disadvantage including education and religious beliefs. What is lacking is a comprehensive understanding of how they achieve this to redress disparity.

Conclusions

Analysis of the two pieces of commissioned research has identified five areas in which blood cancer patients from minority ethnic backgrounds have specific unmet needs. These are:

1. **Diagnosis:** There are additional barriers to diagnosis among patients from an ethnic minority background. Delays to diagnosis could lead to greater disease severity and progression among this patient population.
2. **Information and support:** There is an urgent need for better and more inclusive information and support for patients from minority ethnic backgrounds across their blood cancer journey.
3. **Culturally sensitive care:** Personalised care offered to patients from minority ethnic backgrounds needs to reflect cultural diversity to ensure treatment, care and support are accessible and inclusive.
4. **Barriers to patient empowerment:** The complexity of blood cancer is particularly challenging when coupled with language and communications challenges and clustering of disadvantage in particular ethnic groups, and leads to patients feeling disempowered within their treatment and care journey.
5. **Data:** Data collection and reporting must be improved to allow policymakers, NHS providers, and charities and patient representatives to better understand and address the causes of disparity in need and experience of patients from minority ethnic backgrounds.

Next steps

The BCA presented these findings in a roundtable forum of charities, patients, Parliamentarians, and policy stakeholders on 23rd November 2022. Following that constructive discussion, the BCA will now work on developing potential policy initiatives that could drive improvements to address unmet need among patients from ethnic minority backgrounds across the five key areas identified.

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