



**Blood
cancer
UK**

Ethnic disparities in blood cancer

A collation and summary of available literature and data.

Blood Cancer UK

Contents

Section I

Introduction and context	4
Introduction to disparities	4
Challenges in drawing firm conclusions	4
Key Findings	5
Incidence	5
Multiple Myeloma	5
Lymphoma	6
Leukaemia	6
Outcomes	6

Section II

Unmet needs	7
Patient Experience	8
Diagnostic delays	8
Communication and information quality	9
Understanding cancer diagnosis	9
Understanding treatment options	9
Space for discussion around needs and concerns.....	9
Patient involvement in decision-making.	10
Access to and usage of support	10
Clinical trials and research opportunities	11
Cultural competence	11
Conclusion	13
References	14

Section I

Introduction and context

This report is a collation of the relevant, available evidence about the ethnic variations in incidence, survival, needs and experiences of people diagnosed with a blood cancer in England - hypothesised to be similar to that of the rest of the UK. It is not an all-exhaustive review but rather aims to broadly summarise the data, relevant research papers, as well as Blood Cancer UK and Blood Cancer Alliance-funded research on the topic.

Blood cancer is the third biggest cancer killer and the fifth most common cancer in the UK¹. The most recent data (obtained following a Freedom Of Interest request) documents over 280,000 people living with, or in remission from blood cancer and around 40,000 new cases diagnosed each year¹. It is also the most common cancer in children, teenagers and young people². With more than 100 different types, blood cancer is commonly categorised into three main subtypes: leukaemia, lymphoma, and myeloma. However, it also includes other conditions such as myeloproliferative neoplasms (MPN).

Introduction to disparities

In addition to other factors, growing evidence shows differences in risk of incidence, clinical outcomes and reported experience of care by ethnicity. Additionally, research commissioned by the Blood Cancer Alliance (BCA) have highlighted unique needs of people diagnosed with blood cancer in comparison to those with solid tumours. Differences in unmet needs have also been found to exist within a diagnosis of blood cancer amongst ethnic groups³. This emphasises the significance of the cultural contexts in which individuals function and navigate health systems and the importance of culturally competent care provision. Cultural competence 'is the ability of healthcare providers and organisations to deliver healthcare services that meet the cultural, social, and religious needs of patients and their families'³. It is becoming increasingly recognised as a key aspect of providing quality care and reducing health disparities.

Challenges in drawing firm conclusions from the literature

One of the greatest challenges limiting our understanding of cancer disparities lies in the lack of available, high-quality, granular data. Data collection and reporting by ethnicity is limited and suboptimal, particularly around cancer outcome and survival in the UK. Data on specific areas are more widely captured in the US and so will be used as proxy measures at relevant points in this report. The collection and consistent reporting of higher quality, systematic data on inequalities must be prioritised. Further robust research on ethnic inequalities in blood cancer and its causes are needed to develop effective solutions.

It is also important to be mindful that health inequalities arise, is experienced by, and should be looked through an intersectional lens. Intersectionality acknowledges that socio-demographics such as ethnicity, socioeconomic status and age, and the inequalities associated with them, interacts, and intersects with one another and do not exist in isolation. The extent of this complexity cannot be adequately summed in this report but is important to recognise the reality of such intersectional experiences. However, whilst recognising that ethnic minorities are likely to have intersecting oppressions that produce a broad range of unequal health disparities, this report will focus on the single axis of ethnicity and blood cancer to allow for a focused, deeper dive. Additionally, the lack of available data by ethnicity makes it difficult to understand the exact extent to which disease patterns differ by ethnicity, and factors such as the intersection of ethnicity and other patient attributes⁴.

An additional caveat which remains is in drawing firm conclusions from previous literature and available data. This is due to several reasons, one of which includes the broad ethnic categorisations used in research. Such groupings do not acknowledge the heterogeneity which exists within each traditionally categorised ethnic group, including the various cultural practises, social values, and health behavioural patterns. An additional challenge is presented by the insufficient numbers of participants and respondents from each ethnic group in tools such as surveys. This means that true inferences of real-life experiences are difficult to conclude and for results to be broken down by sufficient granularity. So, although the quality of data collection and reporting have largely increased over the years, there isn't sufficient detail or completeness of ethnicity recording in national datasets. Therefore, the true extent of ethnic variations by disease patterns, survival and care experiences cannot be adequately understood.

Key Findings

Incidence

Generally, incidence rates for most cancer types are higher in the white ethnic group than non-white minority ethnic groups^{5,6}. However, exceptions to this pattern can be found in some cancer types. Available evidence points to associations between ethnicity and incidence of blood cancer with some minority communities experiencing higher rates of some subtypes of blood cancer^{6,7}.

Multiple Myeloma

Multiple myeloma is found to be more common among people of black ethnicity and appeared to be 2 - 2.5 times higher in the black group compared to the White and Asian groups in previous studies with the risks found to be greater for both men and women^{6,7}. However, recent analysis from Cancer Research UK shows rates of myeloma is now 2.7 – 3.0 times higher in people of black ethnicity⁵. They also develop the disease on average 4 years earlier. Despite this, awareness within the black

community is very low⁸. Available evidence also shows rates of myeloma is lower among British South Asian men compared to their white counterparts⁷.

Lymphoma

Ethnic differences were found to exist in rates of lymphoma within American literature. Examination of broad ethnic categories show lower rates of non-Hodgkin lymphoma and higher rates of Hodgkin lymphoma amongst British South Asians. Recent analysis shows Hodgkin lymphoma is 1.3 times higher in males of Black ethnicity and 1.1 times higher in males of Asian ethnicity compared with the White ethnic group⁵. Specifically looking within that heterogeneous group, Pakistani men and women and Indian men experience higher rates of Hodgkin lymphoma than the Bangladeshi community. Non-Hodgkin lymphoma has been found to be slightly higher in Black African men and women as well as Pakistani men^{6,7}.

Leukaemia

At a glance, men that belong in the white and black ethnic groups have higher rates of leukaemia than men in the British Asian ethnic group who seem to experience lower rates⁶. However, a deeper analysis shows differences within the 'Asian' group with Pakistani men and women, as well as Black African women, have a little higher risk compared to the white group. Some of this pattern also extends to children as when compared to those from White ethnic backgrounds, Asian children appear to have a 30% higher risk, with the risk being greatest in Pakistani children (almost 60%)⁷.

Outcomes

Whilst evidence highlights ethnic disparities in incidence rates, much less is known about the differences in outcomes between ethnic groups diagnosed with blood cancer in the UK specifically. There are significant data gaps on survival from blood cancer by ethnic group in the UK and most of the relevant studies in this area have been carried out in the USA.

Findings from the research done in the US show people from Black and Hispanic ethnicities have decreased survival in acute leukaemia when compared to those from non-Hispanic white background^{4,9}. The drivers of these disparities are likely multifactorial and need to be researched further. However, it may in part be explained by differences in the receipt of treatment by ethnic groups such as chemotherapy being received by lower proportions of black patients, than other ethnic groups^{4,10}. Furthermore, the less favourable outcomes for minority communities may also be partially owed to those groups having lower probabilities of finding stem cell donors for transplants. Donors from Black, Asian and minority ethnic backgrounds make up just 15% of the register, and they have only a 20.5% chance of finding the best possible donor match, compared to 69% for white northern Europeans¹¹.

A study exploring the relationship between childhood cancer survival and ethnicity highlighted a notable difference of outcomes almost always being worse for ethnic minorities than white counterparts, irrespective of diagnosis rate patterns across ethnic groups ¹². An example of this is demonstrated in the lower survival of south Asian children with acute lymphoblastic leukaemia (ALL) compared to children of white origin ¹³. Ethnic variations in blood cancer survival should be researched much closer and actions taken to narrow and remove any variations.

Section II

Unmet needs

Ethnic disparities also extend to care needs and patient experience. Although it can be largely assumed that non-white cancer patients will have differing care needs, research exploring this is also limited. A recent patient-focused study, commissioned by the BCA, has started to evidence the unique unmet needs of people with blood cancer from ethnic minority communities. These additional needs continue through the whole cancer pathway, from diagnosis through to care and support. Unmet needs and poorer patient experience have so far been documented in five areas of the cancer care pathway: diagnosis, information and support, culturally sensitive care provision, barriers to patient empowerment and data ¹⁴.

Delays to diagnoses are a pan-blood cancer issue with approximately 30% of new diagnoses coming through emergency presentation. Equally, over 30% of patients report having to visit their GP at least three or more times before a referral ^{15,16}. Additionally, 11% of blood cancer patients wait at least three to twelve months with an additional 3% waiting more than one year between first thinking there was something wrong with them and seeking medical attention, all which add to the delays ¹⁶. This can be partly owed to the non-specific symptoms, making it difficult for patients and GPs to attribute them to blood cancer. However, these delays are significantly worse for people from ethnic minority communities as they are four times more likely to experience delays in referral for a blood cancer diagnosis ³. This was evidenced through a survey undertaken by ClearViewResearch³ which showed that a much bigger 45% of blood cancer respondents from ethnic minority communities reported having to visit their GP three or more times before referral for testing. Additionally, almost half of their survey respondents reported experiencing feelings of not being taken seriously when explaining symptoms to healthcare professionals and felt dismissed by care providers, all which impacted their mental health ³. Although attributions of blood cancer symptoms to factors such as lifestyle and age have been experienced by patients across ethnic groups, it is important to note the higher likelihood of ethnic minorities feeling less empowered to pursue help-seeking which could cause further delays.

Aside from the journey to a diagnosis, unmet needs were also found in the context of receiving a diagnosis. Experiences of racial discrimination during the diagnosis journey were also reported as well over half of respondents feeling their diagnosis could have been delivered more sensitively than it was³. Patient needs, such as their informational needs, not being met can result in suboptimal experiences of care.

Patient Experience

The cancer patient experience is a person's experience of care, treatment and support throughout their cancer journey and is an important element of care. It is also evolving as a measure of cancer care quality hence local and national efforts to capture and measure the patient experience. One such effort is the annual National Cancer Patient Experience Survey (NCPES). Evidence collected from the NCPES and supplementary research analysing experience, have shown consistent patterns of differences in reported experiences of cancer care between groups such as ethnic groups¹⁶⁻¹⁹

Ethnic minorities with blood cancer have been found to evaluate their overall care experience more negatively than their white counterparts^{4,16,18,19}. The 2019 NCPES results showed that amongst blood cancer respondents for whom ethnicities were reported, those from Asian backgrounds scored the lowest on average, followed by those from Black ethnic background and White patients scored the highest⁴. Deeper explorations of sub-group comparisons are limited by the continuously low number of respondents which result in data suppression when minimum response rates are not met. It has also been found that ethnic disparities of reported care experiences are larger for older patients from ethnic minority groups than for younger patients belonging to the same minority communities. This could be explained by older patients being more affected by matters of language or cultural competence than younger generations who have been raised in the UK¹⁹.

In addition to disparities in overall experiences of care, ethnic inequalities have also been found in several domains of experience ranging from promptness of diagnostic suspicion in primary care resulting in diagnostic delays, through to comprehension of health information, involvement in decision making and access to support^{4,16,18,19}. Below is additional data extracted from the two most recent NCPES' evidencing this.

Diagnostic delays

People from ethnic minority communities report facing higher barriers and longer delays to diagnosis.

The 2019 NCPES showed 32% of respondents who identify as Asian felt that the wait before their first appointment with a hospital doctor could have been a bit or a lot sooner which is nearly double the percentage compared to White respondents⁴. The 2022 NCPES results showed that while 63% of White respondents had to speak to their GP only once or twice before being diagnosed with blood cancer, the same could be said for only 46% of Black respondents and 42% of Asian respondents¹⁶. This means 37% of White, 54% of Black and 58% of Asian respondents saw their GP at least three times or more before being diagnosed with a blood cancer.

Communication and information quality

Ethnic minority groups score notably lower in areas pertaining to the quality of information they receive and how well they could understand the information presented to them along their cancer journey.

Similar disparities across the domain of communication and information were reported in the 2022 survey with only 39% of Asian respondents and 44% of Black respondents reporting that the referral for their diagnosis was explained in a way they could completely understand compared to 54% of white patients¹⁶. Disparities were also reported in the comprehension of diagnostic test results with only 64% of Asian and 69% of Black respondents feeling their diagnostic test results were explained to them in a way they could completely understand, compared to a larger 75% of white respondents feeling the same¹⁶.

Understanding cancer diagnosis

Shockingly, consistently lower scores were scored across ethnic groups when it came to understanding the blood cancer diagnosis itself with only 66% of Asian, 69% of Black and 69% of white respondents respectively feeling their diagnosis was explained in a way they could completely understand. These low scores indicate significant room for improvement¹⁶.

Understanding treatment options

Similar disparities were also found in the comprehension of treatment options with only 72% of Black, 76% of Asian, and 80% of white respondents who felt their treatment options were explained in a way they could completely understand¹⁶.

Space for discussion around needs and concerns

Prior to treatment, only 69% of Asian, 73% of Black and a lower 70% of White respondents were definitely able to have a discussion about their needs or concerns. When compared to the 2021 CPES, this is an area which has slightly improved for ethnic minorities but have decreased for white respondents. An area where ethnic minority patients have more positive or similarly positive

experience is, for those who were able to discuss their needs, in the provision of written care plans—a finding concordant with previous research. Indeed, in the 2021 NCPES, it was reported that a member of the patients' care team helped 97% of Asian respondents, 95% of Black respondents and 94% of white respondents to create a care plan to address those needs or concerns ¹⁶.

Patient involvement in decision-making.

Ethnic minority patients report poorer experiences of involvement in their treatment decisions.

The disparities which exist in the comprehension of information presented to ethnic minority patients unsurprisingly spill over into their involvement in treatment decision-making. This domain of experience has been more widely explored and strong evidence exists to show that ethnic minorities are more likely to report a negative experience of involvement in decision-making than their white counterparts ¹⁹. This is re-highlighted in the most recent CPES with only 68% of Black, 74% of Asian, and a higher 77% of White respondents reporting they were definitely involved as much as they wanted to be in decisions about their treatment ¹⁶. This is crucial as more positive experiences of involvement in treatment decisions reduce decisional conflict, result in greater contentment about treatment decisions and overall better well-being ¹⁹.

Access to and usage of support

Patients from ethnic minority communities feel less able to discuss their worries and fears with hospital staff and receive less support from both the hospital, and community and voluntary services throughout their journey.

Only 75% Asian respondents definitely felt they got the right level of support for their overall health and wellbeing from hospital staff, compared to 78% of White respondents ¹⁶. Black respondents scored higher in 2022 than 2021 (70% vs 77%). Ethnic disparities were also found in patients being able to discuss their worries and fears with hospital staff and in their access to wider support options during treatment. Disparities were also found in accessing emotional support following treatment with only 23% of Asian respondents saying they definitely could get enough emotional support at home from community and voluntary services, compared to 28% of white respondents ¹⁶. Compared to the previous year, the most significant improvement was observed for those from the Black ethnic group as only 17% of respondents said they definitely could get enough emotional support at home from community and voluntary services post-treatment compared to a much larger 41% in 2022.

Clinical trials and research opportunities

Clinical trials and research are important to improve the care and treatment of people who have cancer. For some, taking part in a trial may be their best treatment choice as they can gain access to and benefit from new treatments that they would otherwise not have ⁷. As presentation of disease and responses to treatment can vary considerably based on factors such as ethnicity, diversity in blood cancer clinical trials is critical to the development of therapies that are effective in all populations. However, ethnic minorities are often underrepresented in such trials which perpetuates health inequalities. This underrepresentation is due to a myriad of factors, both patient-related and those relating to professional practices, one of which includes a lack of awareness and visibility of opportunities to take part ⁷.

The 2022 NCPES survey showed that out of the blood cancer respondents who were informed of opportunities for taking part in research, a higher proportion of Black patients than other ethnic groups, including those from White ethnic backgrounds, had discussions about research opportunities ¹⁶. Despite this, they are still underrepresented in trials. Documented pan-cancer issues of mistrust, cultural and language differences and understanding have so far been identified as barriers for ethnic minority participation in research, which may be exacerbated by the complexity of blood cancer itself⁷.

Existing research shows that for those from minority ethnic groups, being diagnosed with blood cancer presents particular challenges and needs for information relating to their disease and treatment options. Culturally sensitive communication and care provision is also a unique additional need for ethnic minorities. However, the NCPES and supplementary research would indicate that these needs are not currently being met on the whole. A point to consider and one worth exploring should be that the reported disparities across ethnic groups may be reflective of variation in the actual provision of care or differences in expectations of quality, known as the 'same care, worse experience hypothesis' or could be the result of both ¹⁸. Research to uncover the proportion of inequalities owed to actual provision versus expectations is undoubtedly crucial to advise effective, targeted improvement initiatives. Therefore, further exploratory research with NCPES respondents from across the ethnic groups to examine the reasons for their scoring would be beneficial.

Cultural competence

Ethnic identity is a significant predictor of cultural values although it doesn't eliminate within-ethnic - group variation ²⁰. Ethnicity, cultural aspects, health literacy and other factors influence the way in which people perceive symptoms, seek care, their expectations of it and treatment preferences. It also influences one's willingness to adhere to professional advice and treatment plans and who

patients believe should participate in making healthcare decisions. Therefore, the importance of these factors cannot be overlooked. Language, ethnic and cultural differences, in addition to socioeconomic factors, are a significant determinant of unequal access to optimal standard care and suboptimal patient experience. It also affects clinical trials participation, utilisation of support and comprehension of information about care and treatment. With this, the notion of culturally competent care provision is being increasingly recognised as a key factor, both at individual and system levels, which could contribute to our efforts to eliminate disparities and reduce the burden of unequal cancer experiences²¹. It needs systems that can personalise health care according to cultural and linguistic differences.

Available evidence highlights that hospitals with higher levels of 'cultural competency' scores have lower levels of ethnic disparity in patient experience²²⁻²⁴. Despite its recognised significance, health services are failing to provide culturally competent care. Examples of this include the instances where patients from non-white backgrounds are not offered wigs or compression bandages that match their skin colour or nutritionists not understanding the needs of Muslim patients undergoing treatment during Ramadan³. However, cultural competence training in the UK is extensively variable as it's not standardised or delivered in a consistent manner. Evidence also suggests the current training does not adequately prepare health professionals to meet the needs of culturally diverse communities²⁵. In Blood Cancer UK's recent survey, an overwhelming majority (93%) of blood cancer specialist respondents agreed there is an educational gap for healthcare professionals to better engage with marginalised communities.

The additional complexity of a blood cancer diagnosis only adds to the criticality to deliver care that is responsive to the individual needs of patients belonging to different cultures. The need for this is demonstrated by the persisting unmet needs of minority ethnic groups uncovered from the NCPES and other primary research^{3, 4, 16, 18, 19}. Therefore, those delivering blood cancer care should be equipped with the knowledge of the concept of culture in its complexity and the skills to deliver culturally responsive care.

Ways to promote cultural competency include the provision of more nuanced training for health professionals. Cultural competence training can empower clinicians to deliver intercultural communication skills and respond to culturally influenced needs with greater agility. It can also help providers uncover practices that act as barriers to different communities and adjust them to better meet the needs of diverse patients²⁶.

Other ways to improve competency include building diverse healthcare teams and improving language accessibility. Language barriers can hinder patients from adequately describing symptoms, and clinicians from effectively explaining diagnoses and treatments. Cancer care can be made more

accessible if healthcare providers increase efforts to learn about the populations they serve by collecting demographic data and through community engagement. This will allow for targeted improvement efforts e.g. hospitals can discover their local patients could significantly benefit from interpreters in for example, Urdu or Korean or that a significant proportion of their local population would require halal dietary options during hospital stays ²⁶.

Limitations

The findings from this report must be interpreted with caution and a few considerations should be borne in mind. Despite a broad search strategy, some studies may have been missed. Furthermore, the lack of granular, available data on ethnicity limits and presents challenges in drawing firm conclusions. Additionally, self-reported data, like that seen within the cancer patient experience survey (CPES), is subject to several potential sources of bias. Although the CPES is a national survey, the very low response rates mean its results may not be an accurate representation of the population. The report includes research conducted outside of the UK where there are substantial data gaps within the UK itself. However, inherent differences in the population and healthcare system should be noted when interpreting those findings.

These limitations make it challenging to synthesise findings and limit definitive conclusions. They must be considered to avoid a non-comprehensive and limited understanding of the issues around ethnic disparities in blood cancer.

Conclusion

Findings from this report collating the key, available evidence around ethnic disparities in blood cancer could steer improvement efforts to target people who are at greater risk of being diagnosed, or those who confer a higher risk of poorer outcomes and greater disparities in experiences of care. Interventions can, for example, include the provision of additional information and emotional support or increased time and access to communicate with health professionals. As research exploring ethnic variations within blood cancer is limited in the UK context, it would be beneficial to further explore specific areas. Namely, follow-up research with NCPES blood cancer respondents across ethnic groups who scored lower would provide better clarity on the drivers of lower patient satisfaction.

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