



CLEARVIEW
RESEARCH

Blood Cancer Patient Experience for Black, Asian and Ethnic Minority Patients

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About Us

ClearView Research (ClearView/CVR) is an audience insight and strategy agency. We are specialists in research, evaluation and engagement projects with young people, minority ethnic groups, culturally diverse communities, people with protected characteristics and those who often go unheard. We are committed to ensuring that our work is inclusive and equitable. We strive to ensure that our participants enjoy the research process and find it accessible, engaging, and empowering. We ensure that their voices are central in the materials (e.g., reports and frameworks) that we produce. We work best with organisations who give a damn and want to make a genuine impact. We are an MRS company partner, and we uphold and act in a manner compliant with the strict ethical and rigorous rules contained in the MRS Code of Conduct.

Find out more at:

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About the Blood Cancer Alliance

Every 20 minutes in the UK, someone is told that they have blood cancer.

There are more than 100 different types of blood cancer. Most of these are types of leukaemia, lymphoma, and myeloma. However, the term "blood cancer" also includes other conditions such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN). Sometimes, the type of blood cancer can change as cancer develops.

The Blood Cancer Alliance (BCA) is a coalition of charities that represents people affected by blood cancer. We are united by our goal to improve their experiences and outcomes, and believe that effective engagement with policy makers is vital if we are to achieve that shared goal.

- Our vision is that blood cancer will be recognised by policy makers as one of the 'big five' cancers.
- Our mission is to work collaboratively to raise the profile of blood cancer issues within UK cancer policy.
- Our audiences are those with the ability to influence cancer policy in the UK, including government and parliamentarians.

The current members of the BCA are: African-Caribbean Leukaemia Trust; Anthony Nolan; Blood Cancer UK; CLL Support Association; CML Support Group; DKMS; Leukaemia Care; Leukaemia and Lymphoma Northern Ireland; Leukaemia Cancer Society; Leukaemia UK; Lymphoma Action; MDS UK; Myeloma UK; Race Against Blood Cancer and WMUK.

More information about the BCA can be found in the attached Terms of Reference and on our website <https://www.bloodcanceralliance.org>.

Table of Abbreviations

BAME	Black, Asian and Minority Ethnic
BCA	Blood Cancer Alliance
CNS	Clinical nurse specialist
CPES	Cancer Patient Experience Survey
NCIN	National Cancer Intelligence Network
NCPES	National Cancer Patient Experience Survey
ALCL	Anaplastic large cell lymphoma
CML	Chronic myelogenous leukaemia
MDS	Myelodysplastic syndromes
DKMS	Bone marrow donor centre
MPN	Myeloproliferative neoplasms
MRS	Market Research Society



Introduction / The Why?

In England, there are well-documented health inequalities when comparing ethnic minority groups to White populations. While cancer diagnosis is less common among the UK's Black, Asian and Minority Ethnic (BAME) communities compared to the overall UK population,¹ the outcomes are often poorer. Some of the suggested reasons for these poorer^{2,3} outcomes include inequalities in access to timely, relevant, appropriately presented information about cancer, its risks, symptoms, management and the support available.⁴ This can lead to later diagnosis, which in turn leads to poorer outcomes. However, delays in seeking a diagnosis are not the only reason that people from ethnic minority communities are receiving later diagnosis compared to their White counterparts. Research shows that there are longer referral delays from the first GP visit to the first hospital appointment for patients from ethnic minority communities.⁵

Therefore, although factors such as lack of information and socioeconomic status can contribute to and play a role in health inequalities, cultural and structural racism is adversely affecting health in ethnic minority communities. This is common across all diseases, including cancer. The King's Fund publication⁶ concluded that racism and discrimination partly contribute to increased health care inequalities and that ethnic minority communities have poorer access to health care and poorer experiences of care and treatment where they do receive it. A recent study by ClearView Research for the Joint Committee on Human Rights also found that the majority of Black people in the UK do not believe their health is equally protected by the NHS compared to White people.⁷

However, one of the biggest challenges when it comes to inequalities in cancer

diagnosis, care, treatment and support is the lack of sufficient and accurate data. The current information we can access on cancer diagnosis and incidence in the UK is limited. The latest data from the Office for National Statistics (ONS 2011–2014) shows that people from a White ethnic group are more likely to die of cancer than people from a Black or Asian ethnic group in England and Wales.⁸ However, this evidence is not broken down into different cancer types or age groups, leaving very little room for further analysis or exploration. In 2015, the National Cancer Intelligence Network (NCIN) published a report that explored the experiences of different social groups who may be experiencing health inequalities in cancer.⁹ This report found that people from a Black ethnic group have higher rates of myeloma compared to their White counterparts. However, these findings were not age-standardised, and therefore the age differences across the population may have an impact on the findings. More data is needed to explore the impact of ethnicity on health inequality and outcomes in cancer, for example, the stage at diagnosis for different ethnic groups, treatments and secondary treatments, involvement in clinical trials, and outcomes. The NCIN also acknowledged this absence of data in their report, saying that there is insufficient ethnicity information in cancer registrations to be able to determine mortality and survival for different ethnic groups.

In addition to inequalities in cancer diagnosis, care, and outcomes, people from ethnic minority communities also have different needs and experiences that are often overlooked. 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. When patients receive culturally competent care, this increases the quality of their care and their outcomes. However, many reports suggest that healthcare providers are failing to provide culturally competent care, and there are reports of situations where people from black or ethnic minority communities are not offered wigs, compression bandages, or prostheses that match their skin colour, denying their dignity.¹⁰ To create a system where everyone in the UK has equal access to the same care, we need to develop a better understanding of the needs and experiences of all people from all backgrounds.

One of the major ambitions of the Blood Cancer Alliance is to ensure that all people with blood cancer have access to the best care and treatment in the UK, and certainly no worse than people with other types of cancer. They also want to ensure that the NHS is able to best care for people with acute and chronic blood cancers and recognise their different experiences. As a step to achieving this aim, the Blood Cancer Alliance is conducting a large piece of research to identify unmet needs among blood cancer patients in relation to diagnosis, care and support. In the process of developing this piece of research, they identified that there are further and specific unmet needs within the Black, Asian and Minority Ethnic subset of the blood cancer patient population. Therefore, they decided to commission a further research project which will be aimed at identifying specific unmet needs in relation to diagnosis, care and support for blood cancer in patients from ethnic minority communities.

The aim of this research is to gain a better understanding of the lived experiences of people from Black, Asian and ethnic minority communities who have had a blood cancer diagnosis (or have cared for a close friend or relative who has had a blood cancer diagnosis). Most specifically, we were looking

to identify the challenges they had faced and specific unmet needs throughout their journey to diagnosis, treatment, and their access to support.



Project Limitations

During our recruitment phase, many face-to-face support groups were suspended due to COVID-19.

It is important to note that although the insights in this report reflect the lived experience and reality of the people who took part in this research, our findings cannot be generalised to represent the wider population of all people from Black, Asian, and ethnic minority communities who have had a blood cancer diagnosis.

Methodology

Literature Review

We conducted a rapid literature review of the grey and academic literature to understand more about the challenges and unmet needs faced by Black, Asian, and ethnic minority communities who have had a blood cancer diagnosis.

Qualitative Participatory Design

It seems that the voice of people who are from Black, Asian, and ethnic minority communities who have had a blood cancer diagnosis is largely missing from most discussions about their care and treatment. The Blood Cancer Alliance and ClearView both recognise the importance of meaningfully including people in decisions that affect them. To make sure that the voices of people from Black, Asian, and ethnic minority communities who have been diagnosed with blood cancer are central to this research, we established a diverse co-creation group of six paid advisors from across Great Britain who have had a blood cancer diagnosis (or have cared for a close relative or family who has had blood cancer). The co-creation group worked closely with the ClearView Research team

and the Blood Cancer Alliance to inform the research design and interpretation. The six advisors were from a mixture of ethnic backgrounds and genders, aged between 25 and 61 years, from across the UK. The group met eight times virtually via Zoom over a three-month period.

Online Survey

An online survey was developed in collaboration with the co-creation group, the Blood Cancer Alliance, and the ClearView Research team. The survey was translated into the following four languages:

- Arabic
- Chinese
- Gujarati
- Urdu

The survey was launched on 26 July 2021 and closed on 13 September 2021. The survey was advertised using both our and the Blood Cancer Alliance's personal networks and existing databases. We also used targeted advertising on social media and posted leaflets to haematology centres across the UK. We received 22 responses from people who

identified as coming from a Black, Asian or ethnic minority background from across the UK who have had a blood cancer diagnosis themselves or have cared for a loved one with blood cancer.

The results from the survey helped us to identify areas that we wanted to learn more about in the exploration labs and the interviews. The three main findings from the survey were as follows:

1. 41% of respondents felt that their concerns about their symptoms were not taken seriously by the healthcare professionals at their GP practice

Before respondents received their diagnosis, nearly 1 in 5 visited their healthcare professional at their GP practice five or more times about health problems caused by cancer. Many of these (41%) felt that their GP was not taking their concerns about their symptoms seriously. We wanted to understand more about why participants felt that their concerns about their symptoms were not taken seriously by the healthcare professionals in their GP practice.

2. 45.5% of our survey respondents did not understand the explanation of what was wrong with them when they first received their diagnosis

When respondents first received their diagnosis, nearly half (45.5%) did not understand the explanation of what was wrong with them. We wanted to understand more about why people felt that they did not understand the explanation of what was wrong with them when they first received their diagnosis.

3. 27.3% of our survey respondents felt that they were not involved as much as they wanted to be in decisions about their care and treatment

We wanted to understand what prevented over one quarter (27.3%) of respondents from being involved as much as they wanted to be in decisions about their care and treatment.

Workshop Session

We facilitated a workshop with the co-creation group and Blood Cancer Alliance, where based on the findings from the survey, we decided which areas would be explored further in the exploration labs and in the 1-2-1 interviews. The following topics were agreed upon:

1. Journey to diagnosis
2. Getting a diagnosis
3. Exploring treatment options
4. Care and support

11 people were selected to participate in the qualitative stage of the research on a first come, first served basis.

Exploration Labs

Exploration labs are similar to focus groups. The exploratory labs allow participants to share their experiences, views, and ideas and incorporate engaging visual and graphic methods, where participants can draw and map out their responses. From our experience and evidence from the literature (Bagnioli, 2009), participatory methods work well as they break down barriers to engagement in the research process. The demographics of the participants in the exploration labs and 1-2-1 interviews can be found in Appendix 1.

Findings

Journey to Diagnosis

Patients from Black, Asian and ethnic minority communities are four times more likely to have delays in referral for their blood cancer diagnosis

Blood cancers are the fifth most common cancer type in the UK and the third biggest cancer killer, yet they still take longer to be diagnosed than other cancers. The 2019 Cancer Patient Experience Survey (CPES),¹¹ published by NHS England, found that a quarter of people with blood cancer had to visit their GP three or more times before receiving a diagnosis. This is a serious issue because if people are forced to make several visits to their GP before being diagnosed, then their treatment may not be as successful as those who are diagnosed earlier, potentially leading to poorer or fatal outcomes.

In the latest (2019) National Cancer Patient Experience Survey (NCPES), 10% of cancer patients report having to visit their GP three or more times to get a referral to hospital to be tested for cancer. For those who ultimately got a diagnosis of blood cancer,¹² this figure was 25%.¹³ In the NCPES, 21% of those who identified their ethnicity as Black, Asian, Mixed or Other reported having to visit their GP three or more times before getting a referral to hospital.¹⁴ In our survey, 45.5% of patients from ethnic minority communities reported visiting the GP three or more times about health problems caused by blood cancer before receiving a referral, with one in five respondents visiting five or more times. This shows that there are inherent delays in getting a diagnosis of blood cancer, and that these delays are significantly worse for patients from ethnic minority communities.

Blood cancer patients can experience a range of physical symptoms, depending on

the type of blood cancer. In our exploration labs and interviews, participants shared that they experienced the following symptoms:

- Persistent weakness and fatigue
- Bruising
- Low immunity and having colds and coughs that are difficult to get rid of
- Feeling irritable and 'out of sorts'
- Headaches
- Night sweats
- Passing blood
- Experiencing pain in the body

Almost half of participants did not feel as though they were taken seriously when they explained their symptoms to the GP

41% of participants who took part in our survey told us that before they received their diagnosis, they did not feel that their concerns about their symptoms were taken seriously by healthcare professionals, such as the GP.

In the exploration labs, participants told us that they felt that the main reasons they were not taken seriously by their GP were their lifestyle and age. Participants shared how the GP would suggest that their occupation was causing symptoms such as fatigue or irritability, or that participating in sport was the cause of bruising.

"The doctor just gave me iron tablets, but my body was just absorbing it all. They just blamed it on my lifestyle and my job."

"I wanted to be referred to a specialist, but the doctor even said to me, 'Oh, you're a big girl!' I think, because of my age, he just assumed that it wasn't cancer. I'd not been to the GP in years up until that point."

When their concerns were not taken seriously, participants shared how this had a negative effect on their mental health: *"I felt like a fraud. I knew something wasn't right, and my GP wasn't being straight with me."* When faced with this situation, where they wanted to get to the root cause of the problem, participants felt that they had no other option than to insist on further tests and to tell their GP, *"I know my body better than anybody else."*

Many experienced racial discrimination during their diagnosis journey

This research has found that implicit racial/ethnic bias persists when Black patients report their concerns to clinicians. Shockingly, some participants in our research shared that they had received discriminatory comments from clinicians about the colour of their skin.

In an exploration lab, a participant shared how their father had an allergic reaction to the medication the GP gave them before they were diagnosed: *"When we called 911, staff were saying things like 'Is his skin pink or blue?' He's a Black man."*

There was consensus in the exploration lab that comments like these are something that Black people just *"get used to"*.

"I've been there when they've said, 'Oh, it's difficult because I can't see your veins.' She's effectively saying, 'I can't see the blueness because you've got dark skin and this is making my job difficult.' I remember saying to someone before, 'You know, I'm sorry, it's not my fault.' But we just deal with it. There are times when I could have spoken up more, but it makes me think that when they do put the needle in me, they're going to make it hurt or do something to me."

These comments do not give confidence to the patients that they are receiving the best person-centred care possible. They could

also have a real adverse impact on Black patients and how they manage their overall treatment, as well as their likelihood to attend further appointments or seek help and advice from healthcare providers.

Cultural incompetence and the lack of awareness and understanding from healthcare clinicians can have a huge impact on Black patients' trust. Ethnic bias and racial discrimination lower the standards of care that Black patients receive and lead to higher mistrust of the healthcare system overall. When considering blood cancer and given the major role time plays in the survival outcome—time to awareness, time to diagnosis, time to treatment, and overall outcome—this mistrust becomes even more debilitating to patients.

Getting a diagnosis

Participants felt they could have been told about their diagnosis in a more sensitive way

Over half (59.1%) of survey respondents felt that their blood cancer diagnosis could have been delivered more sensitively.

Patients reported that they were often unaware that they were being tested for blood cancer; therefore, when they received their diagnosis it was a shock. In our survey, 86.4% of respondents received their diagnosis from a specialist doctor or consultant at hospital, and of this percentage, over half of the respondents felt that their blood cancer diagnosis could have been delivered to them more sensitively.

Most of the participants in the qualitative research received their diagnosis face-to-face from a GP, a doctor in the A&E, or over the telephone. Only three participants received a letter.

Participants who received their diagnosis face-to-face and over the phone described the initial shock upon hearing a blood cancer

diagnosis: *"The word cancer is alarming."* They described that, often, other bits of information added with the diagnosis can become *"lost"*. Figure 1 shows a word cloud of the words participants used to describe how they felt when they received their initial diagnosis.

"I received a call from my GP. I was trying to write down as much information as I could. I think he mentioned a couple of sites, but for me, it was just background noise."

Another participant felt that they received their diagnosis so insensitively that they were certain that they were the first cancer patient whom that particular clinician had diagnosed in their career:

"I was in A&E, and they came over looking really excited, which was bizarre. 'We know what's wrong with you. It's cancer, but you've got the good kind. You have a chance and we're just sorting out treatments and a bed, so just stay calm and I'll see you later.' I felt so confused. I might have been the first case for him, which may be exciting for him and something he can add his name onto a research project, but for me it was like my whole world was collapsing."

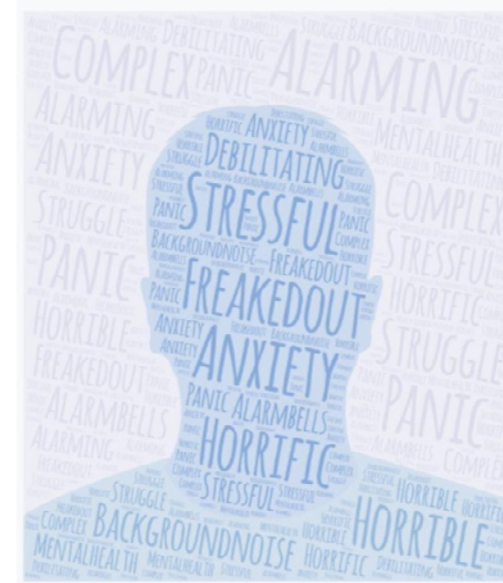


Figure 1 Summary of the words used by participants to describe how they felt when they were told their diagnosis

Participants felt there was no time to deal with their diagnosis and they were rushed into treatment

Research by Blood Cancer UK (2019)¹⁵ found that people with blood cancer are more likely to be diagnosed via emergency admission than many other cancer types. This suggests that the situation is likely to be critical, and therefore the need for time, sensitivity, and empathy towards patients when clinicians are having to deliver this news to patients is even more crucial to the patients' wellbeing.

A number of participants in our exploration labs told us that when they received their diagnosis in A&E, they felt that their condition was so critical that they did not have sufficient time to digest and reflect on their diagnosis, let alone explain to their family members, before they were started on treatment.

"I was in A&E on my birthday, and they told me the morning after my birthday because they didn't have the heart to tell me about it. Before my diagnosis, I was being kept alive by blood transfusions because my blood count markers were so severe. They started treatment within a couple of hours of me receiving my diagnosis."

Only one in seven participants (14.3%) understood what was wrong with them when they were first diagnosed. Patients who have been diagnosed with blood cancer are less likely to understand their diagnosis compared with other cancers.

In our survey, nearly half (47.6%) of respondents told us that they did not understand the explanation of what was wrong with them when they were first diagnosed, and only just over a third (38.1%) understood some of what was being explained to them. This indicates that there is a need for clearer explanations to be given to patients when they are being given their diagnosis.

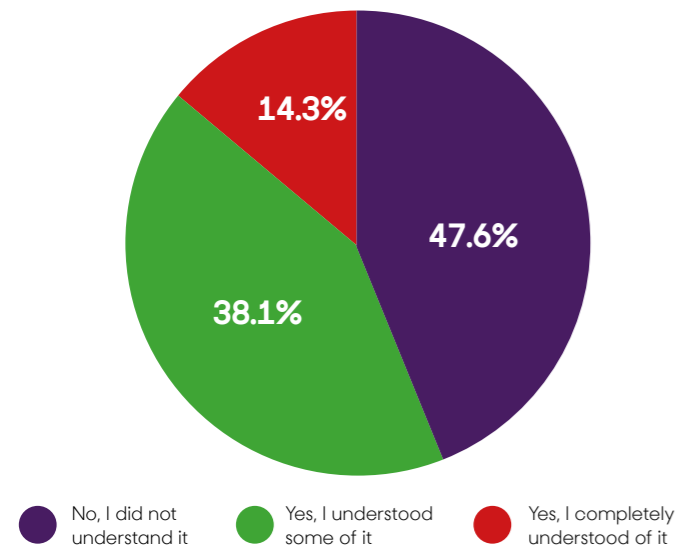


Figure 2 When you were first diagnosed, did you understand the explanation of what was wrong with you?

Patients are afraid to ask clinicians questions and seek information elsewhere

In our qualitative research, a number of participants told us that they did not feel encouraged to ask questions about their diagnosis. Too often, the language used by clinicians was described as "too technical" and difficult to understand. When they did ask questions, these participants felt they were being perceived as a "problem patient."

"Some [clinicians] just roll their eyes at you when you ask questions. I hear too many horror stories where somebody has been given the wrong drug. You have a 100% right to question anything you don't understand."

If patients do not feel encouraged to ask questions, this could fuel the lack of trust that patients have towards health care clinicians. Patients are aware that healthcare clinicians are under a lot of pressure and time constraints, which can make them feel that the clinician does not have the time to listen to them or take them seriously. However, patients need to feel that they can trust their health care clinician so that they are confident that they are being cared for and

treated in the best way possible to suit their individual wants and needs.

"I was in the waiting area with my sister, and a consultant walked past. He looked really busy, and my sister said, 'I hope he isn't the one you're going to see; he just looks like he's under a lot of pressure.' Unluckily for me, it was that one. I appreciate that a consultant's bedside manner might not be the best, but you are giving someone some devastating news. You've got to realise the impact of what you say and just even a bit of clarity, with some information that they can digest."

Some participants described how they were able to use the internet and conduct their own research if they needed further information about their diagnosis. They felt that this helped them get the treatment and care they needed. One consultant told a patient, *"This is your disease. You take charge of it."*

However, there was a consensus that the older generation, those not born in the UK, and some cultures who are less inclined to question authority, will typically not take control in understanding their diagnosis and treatment options.

Some of the reasons that participants gave for not asking more questions at the time of diagnosis included not knowing how to use the internet, not feeling confident or encouraged to ask questions, or generally not understanding what they were being told (either due to a language barrier or the clinician's vocabulary being too technical). Participants reflected that this resulted in them just "getting on with it" and accepting what the clinician or the expert was telling them.

"My dad was prescribed a trial drug and was told by the GP to sign a form. When

he brought the form home, we realised that it actually had somebody else's personal details on it. The trial drug was for an illness that had nothing to do with my dad's blood cancer."

By not asking questions, patients could end up being left in the dark even further about their diagnosis and treatment options. This has the potential to increase health inequalities, where those who do not feel encouraged to ask questions receive lower standards of care.

Exploring Treatment Options Patients are not involved in making informed decisions about treatment

Over a quarter of survey respondents (27.3%) who were from ethnic minority communities felt that they were not involved as much as they wanted to be in decisions about their care and treatment. This is in stark contrast to the very small percentage (3%) of all people with cancer surveyed, who reported that they were not involved as much as they wanted to be in decisions about their care and treatment in the National Cancer Patient Experience Survey (NCPES).¹⁷

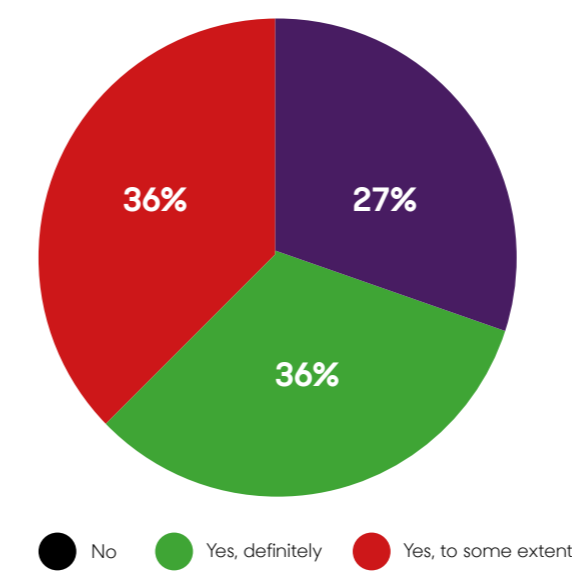


Figure 3 Were you involved as much as you wanted to be in decisions about your care and treatment?

Similarly, only 36% of survey respondents who were from ethnic minority communities felt

that their treatment options were completely explained to them before they started treatment, compared to 75% in the NCPES.¹⁸

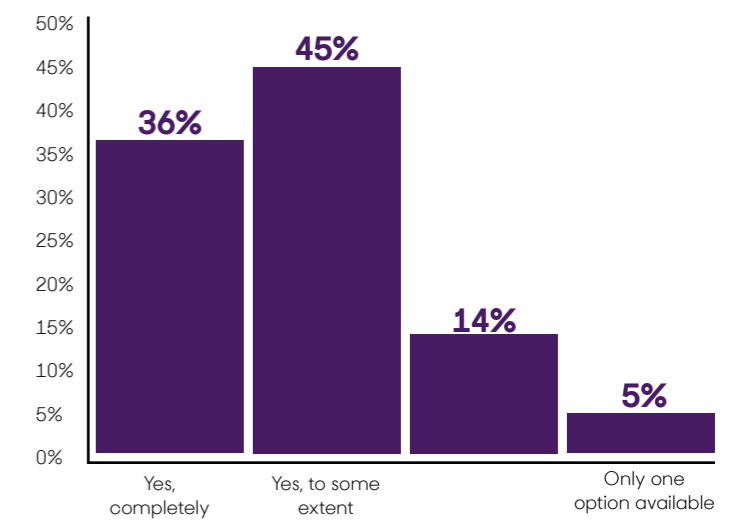


Figure 4 Before your blood cancer treatment started, were your treatment options explained to you?

Participants in the exploration labs described how they had to make uninformed decisions about their treatment. They described situations where they were only given one option; they felt like there was a rush to make a decision about treatment, and the consultant had no time to explain it to them.

"I wasn't given a choice at all about my treatment option because I was diagnosed at such a late stage and I was critical in terms of treatment, they just put me on treatment. So I was literally signing consent forms as soon as I was diagnosed. The consultant didn't really explain anything to me. He basically passed me off to the nurse who was looking after the haematology at the time to go through the implications of my treatment, what it meant for things like my fertility and side effects and symptoms."

"It's always the nurses I have to go to, to try and get any information that the consultant might know by name, and sometimes it's just really difficult. It feels like you get divorced and quite distant from the consultant who's meant to be caring for you."

"But the only symptom that he could come home and tell me about was that he probably couldn't have any kids, but he's 60 so it's not something he's really worried about. But I think he wasn't really made aware of the more prominent side effects, which he started to see very quickly, which was things like an upset stomach that meant he needed to be close to the toilet, stuff like that."

have made them look like difficult patients, but that it was important to them and their families to understand the impacts of the different treatments, so they had to do it.

"But as a parent, you know, you need to understand it from my perspective. I need to be comfortable. I need to be able to share with my family so they're comfortable and they don't kind of worry due to lack of information."

"When they put something on the drip, I'd ask them what it was. I don't like not knowing what I'm taking. And I just hear too many horror stories where somebody has been given the wrong drug. That's why I question things, and I was lucky that the nurses were quite patient with me, but I do get your point that there are nurses out there who probably think—they do the eye-rolling thing—that, 'Oh no, it's not her again' or 'not him again'. It's not helpful. And as a patient, you have a 100 percent right to question anything you feel that you should be [questioning]."

Patients feel like they have no control over clinical trial treatment decisions.

Less than one-third (32%) of those from ethnic minority communities who completed our survey reported being offered the opportunity to participate in a clinical trial, and less than half (43%) felt that they understood the information that was given to them about the clinical trial.

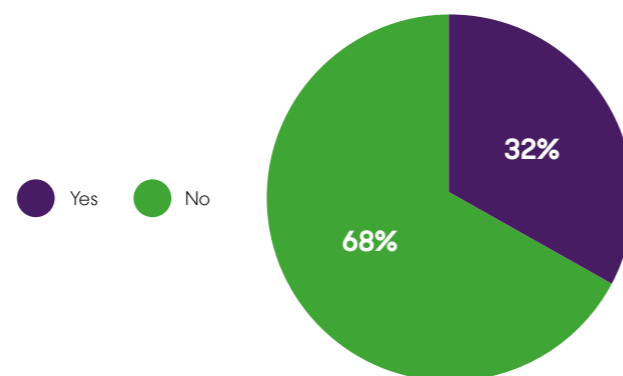


Figure 5 Were you offered the option of participating in a clinical trial?
Minority Patients

Another situation that was given as an example of having to make uninformed decisions about treatment was when a great deal of information was provided to the patient, but they did not understand it.

"Copious pages of documentation about getting involved in a clinical trial. And half of it, I didn't know what it meant... I struggled to kind of understand what the implications of it can be. It's quite scary. And having to sign up to it, you know, in the end it was the right thing for me to do, but it would have been good if someone had kind of talked me through it, helped me through it, because this is a big decision that we're making."

One participant also spoke about the impact this lack of information had on their quality of life. They were not informed ahead of their treatment that one of the main side effects was pain. This meant that they were not expecting or mentally prepared for the pain that they experienced during the treatment.

"I was so angry because I had a very painful bone marrow biopsy. And ... and it wasn't explained to me that it was going to be so painful. So, I just thought it was a normal standard procedure."

Some of the exploration lab participants spoke about how they pushed back and insisted on getting more information or having the information provided explained to them. They spoke about how this may

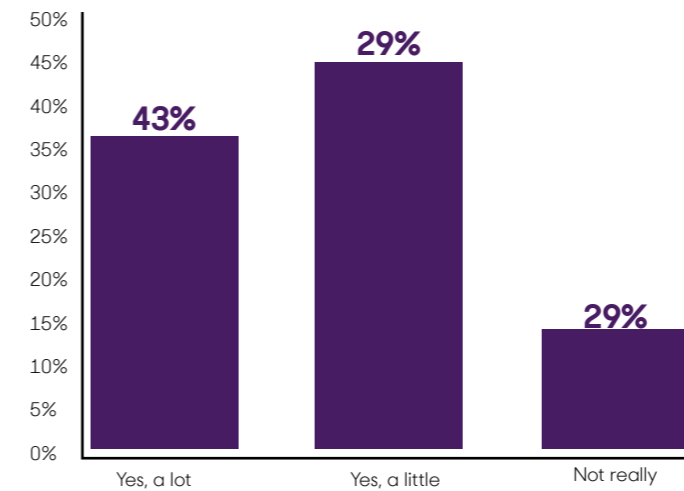


Figure 6 Did you understand any information given to you about the clinical trials?

In the exploration labs, the participants who were offered the option of a clinical trial spoke about there being a lack of information provided until after they had agreed to participate. It was only through pushing and asking questions that they got any further information. This left the participants feeling like they had very little control and could not make informed decisions about their treatment; instead, they had to take a guess and gamble on the outcomes.

"You have two options. Either you go on the standard treatment, or you've got an option to get involved in a clinical trial because you've been deemed to be suitable, go off and decide again. And that was how I was told, there was no information, there wasn't anything. I just had to make a quick decision about what I wanted to do."

"After I signed up for it and it started going further down the line, that's when I was finding out more just through me probing, reaching, challenging."

In some cases, by pushing back, participants also learned that information was not just not being shared with them; it was being left out on purpose to influence them into an uninformed decision. One participant spoke about how, even when she asked about how

many times a treatment had been tested before being offered to them, the healthcare professionals first avoided the question, and when pushed, they found out that they would only be the fifth person it had ever been tested on.

"I said at first, 'How many people have tried it?' And they said, 'Oh, you know, it has been successful so far.' And by then, I had a better understanding of things that were going on. And I said I would like a figure, and I would like numbers. And finally they said, 'Oh, you'll be number five to try it.'"

Care and support

It is important to recognise and understand how diverse a patient's needs can be

Evidence suggests that patient anxieties are reduced when they turn to faith.¹⁹ However, healthcare clinicians may not always take religious beliefs, or other cultural nuances, into account when they are treating or supporting patients and their families through their cancer journey.

In our exploration lab, a participant shared how one parent was struggling to find a clinician who would understand their young son's needs:

"When I was receiving my treatment, I met a mum whose young son was diagnosed with leukaemia. She told me she was struggling to find a doctor who understood her son's needs. He was getting treatment through Ramadan, and the nutritionist they had just wasn't very supportive. It was conflicting with their way of life. It was just very difficult for her."

Healthcare clinicians must provide patients with an opportunity to discuss their religious and spiritual beliefs. In doing this, there is hope

that clinicians can tailor their evaluations and treatments to meet their specific needs.

However, to do this, clinicians need to be welcoming of any questions that patients may have about their diagnosis and treatment and be more understanding of their cultural sensitivities. At the very least, clinicians should be able to refer patients to charities or nurses who can support them.

Family members are not always informed about their loved one's diagnosis

Some participants in our research shared how they had not told their loved ones about their diagnosis. Reasons for this are beyond the scope of this study; however, in one exploration lab, participants reflected that in some cultures the word 'cancer' is taboo: *"In my culture, for people to actually touch on that within a family unit can be seen as a weakness in that person. People just don't talk about their problems or illnesses."*

It seems that in some instances, not telling their loved ones about their diagnosis empowers the individual to come to terms with and understand their diagnosis and the journey ahead of them, at their own pace and in their own time. It is therefore vital that healthcare staff are mindful that, in some cases, family members are not aware of their loved one's diagnosis.

One participant repeatedly received letters from the hospital with 'Blood Cancer' in bold red letters on the envelope, which they had to hide from their family. Even when the participant asked the hospital to stop sending letters, it did not honour their request.

Another participant described that by not telling family, they avoided being pressured to answer questions that they just did not have the answers to. Instead, they had the time to read through the literature from reliable internet sources and watch videos online

about people talking about their condition. In reading widely about the topic, the research participant shared how they have come to terms with their diagnosis and developed a series of questions to ask their clinician.

"I have broken down at certain stages, but I've been reading this book that is helping me deal with the mental side of things. It helps a lot to just breathe and stop, and just to absorb what I have been diagnosed with."

It is important to respect each individual patient's experience and journey. This means allowing them the space to deal with the diagnosis themselves if they choose not to tell family or friends.

Having access to the right information when you need it is key

Many patients reported receiving little or no information about their diagnosis, leaving them very uncertain about the journey ahead. A number of participants in our research used the internet to learn more about their condition. One participant described the negative psychological impact this had on their wellbeing:

"From the outset, there was nothing there. I found myself on the internet, and all I could do was just cry because it was so difficult and negative to read. I know my family was doing exactly the same. But, in reality, that's not what it's like. If someone had just told me the information up front, I would never have resorted to that."

In our survey, 59% of participants reported having received information booklets with further details about their blood cancer when they were diagnosed. However, only half of the research participants found these information booklets useful and inclusive.

"Here, have a leaflet and read through it,' is not going to help anyone who has just been slapped with a cancer diagnosis. When I heard the word 'cancer' I thought my life was ending."

The participants described much of this as being driven by the lack of time, and not feeling encouraged to ask questions with their consultant. Some participants described how it would be much more useful to have someone or somewhere that they could reach out to for support when they were ready and to help them by answering their questions.

"You feel bad asking questions to consultants because they're under a lot of pressure time-wise. In the back of my mind, I'm thinking, 'Right, I've only got ten minutes; I've just got so many questions and they just don't have time for this.' It would have been helpful to be able to talk to somebody, so I could have a kind of more informal conversation and discuss my concerns. That would have been helpful for me."

Having access to a clinical expert is useful and inclusive

Only three participants felt psychologically supported by their consultants, and they had received their diagnosis before 2016. One participant described how they could call their consultants up at any time with any questions they had. They described how their consultant once dropped in on their day off while they were in hospital *"just to see how I was doing. He sat with me, and we just talked about how I was coping."*

The other participant described how only one consultant in five years asked: *"How are you? Forget about your blood, forget about your bone marrow and everything like that. How are you coping with your diagnosis? How are you coping with your symptoms?"*

This support from their consultants had such a positive impact on these two participants that they still remembered it five years later, in 2021.

54.4% of the participants in our survey received the name of a clinical nurse specialist (CNS) who would support them through their treatment.

The majority of participants who received the name of a CNS who would support them through their treatment felt that this was useful and inclusive (83%).

The participants in the exploration labs who received the name of a CNS when they were diagnosed described how useful this support was.

"My CNS nurse really went above and beyond her role."

Charities can be a key source of information and support when accessible

Only 40.9% of participants received information about charities that exist to support people specifically with blood cancer when they received their diagnosis.

Participants who received information or support from charities reported receiving financial support and psychological support.

"I was put in touch with a Macmillan nurse who physically came to see me and was with me at every stage throughout the six months I was in hospital. I felt reassured that I had this sort of mental support. Without them I would have really struggled."

Positive examples of financial support were:

- One participant shared how the Willow Foundation had paid for their 21st birthday party.

- The Ronald McDonald Foundation gave financial support to a family who came from abroad so that they could stay near the hospital while their loved one was going through treatment.
- The NHS paid for a family member to come from abroad who was a donor to a participant.
- A CNS nurse supported a patient who was a student at the time to apply for mitigating circumstances with the Student Loans Company, who struck off the first year.

Some participants have kept in touch with the people who have supported them over the years. In one example, a participant shared how a member of the ALCL charity came to visit them in hospital after they had had their first child, offering ongoing emotional support:

"They realised I was down at the hospital all alone and came down. They brought my son a big teddy bear; he's seven now, but he still has that teddy bear. Each year since I've had my transplant we do something different to celebrate it, sometimes it's something small, sometimes bigger. Over the years, whenever I have the opportunity to help them, I fundraise for them so I can give back."

The financial and psychological support that participants received has had positive long-term and life-changing impacts on the participants. This goes to show the true impact that charities have on patients' lives.

"Charities need to do a bit more by getting people from the local community involved to showcase stories that come from people like us."

Although over three out of four participants in our survey (77.8%) found the information useful they received about charities that exist to support people specifically with blood

cancer, less than half (44.4%) found them inclusive.

Some participants who were diagnosed under the age of 25 felt that support groups were generally not for them: *"Support groups wouldn't really be for my age range and to be honest, I was told that."*

All of the participants felt that information and support about blood cancer from charities needs to be marketed in a way that demonstrates that it is diverse and inclusive of all cultures: *"They need to portray themselves as inclusive or people will think this charity is not for me and continue to struggle accessing the support they need."*



How can charities be more inclusive?

When we asked how charities and organisations can best support people from Black, Asian and ethnic minority communities, they suggested:

- 1. Showcase stories and case studies about people from Black, Asian and ethnic minority backgrounds.** Having someone who has experienced what they have experienced and who looks like them would grab people's attention, raise awareness about blood cancer, and increase the willingness to talk about it in some cultures.
- 2. Raise awareness:** about the need to increase stem cell donors from ethnic minority communities.
- 3. Provide a clear guide that is available in different languages and tailored to different ethnic groups on how to support a loved one with blood cancer:** This information guide should be written in layman's terms and given to loved ones so that they can understand and support their loved one through their blood cancer journey. This guide should be tailored to people from ethnic minority communities, with tips on how to share their diagnosis with their loved ones. The guide should also include a list of helpful myth-busting questions or quotes that might help patients on their blood cancer journey.
- 4. Educate healthcare professionals about cultural diversity and sensitivity:** Develop a clear guide or training package tailored to the medical profession. This guide or training package would help clinicians to be more understanding and aware of different cultures and cultural sensitivities.



Conclusion

This research has highlighted the lived experiences of people from Black, Asian and ethnic minority communities who have had a blood cancer diagnosis. Almost half of the participants in this study reported a delay in their referral to hospital to get their blood cancer diagnosis. Delays in referral lead to delays in diagnosis, which can often lead to blood cancer being diagnosed at a later stage, resulting in poorer outcomes for the patient. The participants felt that the main reasons for these delays were due to their skin colour or ethnicity. They reported situations where GPs claimed their symptoms were due to their lifestyle or their type of employment, and even situations where they were asked questions about their skin colour that were not relevant to people who are not White, such as *'Has his skin turned blue?'*

This discrimination can have a compounded effect on patient experience, as not only does it delay their diagnosis and treatment, which can result in poorer outcomes, but it also puts into question their trust in the health system and the people who work within it, meaning that they may not ask for help in the future, or even trust the advice that is being given to them. This leaves patients from ethnic minority communities in a very vulnerable and isolated position where they must figure things out for themselves, and many reported going to the internet, friends, or family to do just that. However, getting their information from unreliable sources can have a detrimental effect on both their mental and psychological health as well as their physical health and survival.

The real experiences we heard during this research also show that the discrimination

experienced by people from ethnic minority communities did not stop at diagnosis. The participants shared stories about continued experiences of discrimination throughout their treatment and care. They reported being rushed into treatment before fully understanding their diagnosis, not being given the time or opportunity to ask questions, and being made to feel like they were annoying the healthcare staff when they pushed back and insisted on getting more information. Some of these experiences have been reported by people from White ethnic communities in the past, but the evidence presented in this report shows that these experiences are consistently more common for people from ethnic minority communities.

As well as discrimination, the participants in this research also spoke about the negative impact of not being understood on their patient experience. They shared examples, such as receiving letters from the hospital with 'Blood Cancer' on the outside of the envelope and having to hide these from family and friends, and situations where healthcare professionals did not take into consideration their cultural or religious needs, such as Ramadan. Having a blood cancer diagnosis is a huge and life-disrupting challenge. Patients need to be able to maintain a certain level of control over other aspects of their lives as they navigate this challenge. Supporting patients' personal, cultural, and religious circumstances is an important part of helping them to achieve this and a key component of their care.

To reduce health inequalities and best support people from ethnic minority communities through their blood cancer diagnosis, we need

to acknowledge and dismantle the existing discriminations that exist in the healthcare system that are creating barriers to equal care and support. However, this alone will not solve the current problems. As well as eliminating existing discrimination, we must begin to provide a healthcare system that can take the time to understand a patient's personal, cultural and religious needs so that we can begin to provide the level of person-centred care that has been set by the Care Quality Commission, the independent regulator of all health and social care services in England.



Appendix 1 Demographics of the exploration lab and interview participants:

Ethnicity	Total
Black - African	6
Black - Caribbean	3
Mixed - White and Black African	1
Mixed - White and Asian	0
Asian - Indian/ Pakistani	3
Asian - Chinese	2
Asian - South East Asian	2
White - European/ Other white	5
Total	22

Age	Total
25-30	1
31-35	1
36-40	3
41-45	3
46-50	3
51-55	5
56-60	1
61+	5
Total	22

Gender	Total
Man	9
Woman	13
Total	22

Employment Status	Total
Retired	4
Unemployed or not working	3
Working full time (30 hrs or more)	11
Work part-time (8-29 hrs)	1
Other	3
Total	22

Location	Total
East Midlands	1
East of England	2
London	8
North West England	1
Other	3
South East England	4
South West Wales	1
Yorkshire & Humber	1
Total	22

Appendix 1: Participant Demographics

- <https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england>
- <https://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-14-197>
- <https://www.nature.com/articles/6691101.pdf?origin=ppub>
- <https://diversityhealthcare.imedpub.com/critical-review-of-literature-on-ethnicity-and-health-in-relation-to-cancer-and-palliative-care-in-the-united-kingdom.pdf>
- <https://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-14-197>
- <https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england>
- <https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/correspondence/The-Black-Community-Human-Rights-Report.pdf>
- ONS (2014) Ethnic differences in life expectancy and mortality from selected causes in England and Wales: 2011 to 2014: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/articles/>
- PHE NCIN (2015) Cancer and equality groups: key metrics 2015 report: <http://www.ncin.org.uk/publications/reports/>
- <https://www.youtube.com/watch?v=jhOlem7Hm-o>
- <https://bloodcancer.org.uk/news/what-can-we-learn-cancer-patient-experience-survey-data/>
- https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf
- <https://bloodcancer.org.uk/news/what-can-we-learn-cancer-patient-experience-survey-data/>
- <https://www.ncpes.co.uk/2019-national-level-results/>
- https://media.bloodcancer.org.uk/documents/bloodwise-delayed-diagnosis-report_RIQgdp7.pdf
- <https://bloodcancer.org.uk/news/blood-cancer-facts/>
- https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf
- https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf
- <https://www.ncbi.nlm.nih.gov/books/NBK493216/>

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