

NO ONE OVERLOOKED:

Experiences of **BME** people
affected by cancer

WE ARE
MACMILLAN.
CANCER SUPPORT



CONTENTS

Introduction	1
BME groups and cancer	2
What we're doing: Macmillan's engagement approach	3
Methodology	4
Findings:	5
a. Emotional and psychological needs	5
b. Physical needs	9
c. Practical needs	12
d. Underlying assumptions and perceptions	16
What Macmillan wants to do	21
What can I do?	21
Acknowledgements	22
References	23



INTRODUCTION

One of the core principles underpinning the health and social care system in the UK is that access to – and appropriate delivery of – the best quality care services is available to everyone. This applies irrespective of race, age, sexual orientation, gender or gender identity, income, disability or religion. And yet, health consistently remains one of the great focal points of inequality¹ and a central concern in public health policy, especially when it comes to cancer.

In 2015 the estimated number of people living with cancer in the UK is almost 2.5 million. Assuming that all existing trends in incidence and survival continue, cancer prevalence is projected to increase to four million by 2030. Considering this, it is vital that the experiences of everyone living with and affected by cancer are taken into consideration so that no one is overlooked, ignored or poorly treated. Robust data about these experiences, therefore, is crucial.

Current methods for data collection about patient experience often target people living with cancer who are easily accessible. The analysis rarely stretches far enough to uncover hidden or latent needs as experienced by 'too-frequently-ignored' communities.

What's more, such quantitative methods only provide a descriptive snapshot without explanations. The drivers of inequalities are likely to be complex and difficult to articulate, resulting in needs that are hidden. By definition, surveys only capture recognised current needs, not hidden or future needs.

Such a lack of evidence into people's experiences will limit our ability to deliver services which truly reach every person living with or affected by cancer. The knock-on effects will include a lower take-up of services, later diagnosis, and an exacerbation of existing health inequalities.

BME GROUPS AND CANCER

There is a great need for more robust cancer data on ethnicity, as the quality of ethnicity recording in routinely collected health data remains poor.² This raises concerns around the completeness and accuracy of analysis when using existing data.

However, we do know from successive Cancer Patient Experience Survey (CPES) reports that black and minority ethnic cancer patients have poorer experiences of cancer services than their White British counterparts. For instance, the recent 2014 CPES showed that BME patients have poorer experiences on nearly all dimensions of care and there are statistically significant differences in 20 specific aspects of care. These include delays in diagnosis and referrals to hospital doctors, the provision of information, communication and interactions with healthcare professionals, and access to help and support.

These findings suggest important ethnic inequalities³ in cancer care.

More research, however, is necessary to fully understand what lies at the root of these results and how to identify ways of addressing poorer experiences and outcomes. Despite improvements in current ethnic data collection, there is still an incomplete picture due to inconsistent ethnic data collection and research. This data and research is crucial if we want to evaluate the quality and outcomes of cancer care and investigate differences in cancer incidence, survival and access to treatment. Without it, the risk increases of not meeting needs appropriately for BME. As a result, experiences of the cancer journey continue to be worse for people in BME communities,⁴ and resource and service commissioning may be inadequate.

WHAT WE'RE DOING: MACMILLAN'S ENGAGEMENT APPROACH

There are several broad principles to our engagement approach aimed at tackling health inequalities:

- To understand the complex issues driving health inequalities and to identify hidden needs, we need more qualitative research that targets specific seldom-heard-from groups of people affected by cancer.
- People affected by cancer are the experts in their experience, and should be equal partners in shaping the future of cancer care. We will support people affected by cancer to prioritise what the most important issues are, identify and test possible solutions, and influence decisions that lead to improvements.
- We will work with a range of partners (including people living with and affected by cancer, researchers, community partners, service providers, and policy makers) to understand needs and co-design solutions that work.

The experiences reported in this document are the first part of this engagement approach for BME people affected by cancer. This research builds on Macmillan's report, ***The Rich Picture: People with cancer from BME groups***⁵ (a document that collated the key available evidence about the numbers, needs and experiences of this community).

In this report, we look in depth, in a qualitative way, at the experiences of a sample of BME people living with cancer at different points of the cancer journey. Following this, we plan to work with people affected by cancer, policy-makers, commissioners and service providers to develop recommendations and develop interventions that will drive improvements in patient experience and reduce inequalities.

METHODOLOGY

To explore the experiences of BME people living with cancer, the study was carried out using a bespoke online engagement forum. It brought together 19 Black and Asian cancer patients with 24 healthcare professionals, diversity specialists and academics with an interest in equality, diversity and cancer.

The sample of 19 participants with cancer included 11 Black and eight Asian patients, 14 who were women and five who were men. Five were aged between 18 and 34, and the rest were aged between 35 and 64, making it a comparatively young group of cancer patients. Everyone had lived in England all or most of their life, was fluent in English, was broadly familiar with the NHS system, and faced no linguistic

barriers in accessing information or communicating with healthcare professionals. Most were diagnosed with one of the ten most common cancers in the UK, and seven had a rare cancer. Two of the participants had two independent cancers, and two others were experiencing recurrences. Six participants were first diagnosed less than a year ago, four between one and five years ago, and nine had their first diagnosis more than five years ago. Ten participants were post-treatment, but others were either undergoing treatment or awaiting treatment (pending a suitable bone marrow donor). Those undergoing treatment were less likely to take part regularly in the research mainly because of prolonged stays in hospitals or physical exhaustion. Finally, in terms of their general health, five had a long-standing limiting condition (in addition to cancer).



Over a period of eight weeks, two professional researchers involved participants in 70 qualitative research and engagement tasks (see Appendix 1). Our main aim was to give a genuine voice to participants, and allow them to define and discuss the issues in their own terms.

FINDINGS

The findings are presented under the following headings: emotional and psychological needs, physical needs, practical needs (including financial and information needs), and underlying assumptions and perceptions.

We have presented the findings in this way as the boundaries between treatment (be it curative or palliative), recovery and post-treatment can sometimes be very fluid. Indeed, most of the experiences the participants living with and beyond cancer in our sample discussed (such as not feeling treated like 'whole people', lacking knowledge and information, poor communications, not feeling involved in decision making, etc) were not confined to specific stages. The participants' experiences also pertained to both primary and secondary care services, as well as to post-treatment and survivorship. Additionally, the same participant could have more than one cancer or have a recurrence, therefore they could be at different stages of the cancer journey simultaneously.

a. Emotional and psychological needs

The Rich Picture: People with cancer from BME groups highlighted a number of emotional and psychological needs, including:

- British South Asian patients reported significantly higher rates of symptoms associated with depression compared with White British patients following a cancer diagnosis (35.1% against 16.8%).⁶

- The lack of conversations about cancers in certain BME communities has had an adverse effect on their likelihood of engaging in cancer screening practices.⁷

Communication

Within the sample, many of the BME participants felt that they had been unable to discuss anything beyond their immediate physical needs with their GPs and hospital doctors. They reported that doctors often did not look at them in the eyes, listen to their concerns and worries, or answer their questions.

'I don't feel like I can ask questions because I feel like I'm a number. I feel like I'm a number because I feel like I'm on a conveyor belt that doesn't even stop. Doctors appear not to have any genuine concern for how you're doing. I understand why: they're not psychologists and they don't have time to listen or take seriously everything you say. But there is something lacking and that makes the whole experience scary, intimidating and rushed.'

I know that time is not on their side though, nor money.'
(Black woman affected by cancer, 35–64)

'They start off treating you as a number and then I fought for my voice to be an individual. Sometimes they forget that you have feelings and you are a person like them. So it's either you become that number and fade into the background, or you fight to show your personality and to be accepted as you.'

(Black woman affected by cancer, 18–24)

'The surgeon lacked people skills. He had no idea about how I felt and was not interested in 'trivialities' like loss of hair, dark circles around my eyes, weight, etc. He told me on several occasions that I had far more serious problems that I should be concentrating on. His response to anything new that I reported to him was, "One more thing to add to your problems." He had no idea that for me to get better, I had to feel good about myself.'

(Asian woman affected by cancer, 35–64)

These problems are not unique to BME patients but, both in our sample and in various years of the CPES⁸, they are found more often in this group of patients.

Level of involvement

Within our sample, there was a large discrepancy between what participants reported as their desired level of involvement and their *actual* level of involvement. This corresponds with findings from CPES that BME patients were significantly less likely than their White British counterparts to report being 'involved as much as they wanted in decisions about care and treatment'.⁹ There was a strong theme amongst the participants in the sample of wanting

to restore some sense of control at a time of great vulnerability.

'As there was a delay in diagnosing my illness, I felt like I had to be quite in charge of my treatment and needed to be pro-active in finding out as much as I could about breast cancer, and treatment options that were available to me. It felt like a burden, as well as empowering, in a situation where I felt I had lost control of my body, although my mind was holding on tight to control my own life.'

(Asian woman affected by cancer, 35–64)

Networks of support

Support groups have been an integral component of cancer care for decades. However, evidence suggests that this component is one in which BME people living with cancer – or caring for someone who is – are less likely to access than their White British counterparts¹⁰. Within this sample, this pattern seemed to be caused in part by the limited supply of, awareness of, and demand for tailored BME cancer support. It did not reflect lack of need. Some of the BME participants and their carers actively sought support but did not find services that met their needs.

'I never felt that I got the right support with my cancer. I felt alone and that no one cared, so I had to do this for myself.'

(Black man affected by cancer, 18–34)

'I think my husband struggled a lot emotionally as it was a big strain on him. He had some support but probably not as much he needed.'

(Asian woman affected by cancer, 35–64)

'Support for carers or family members is thin on the ground. In an ideal world, carers and family members should be supported as part of the overall treatment being offered to the sufferers. If one's carer or family member finds it too hard to cope, their needs should also be taken care of. If not, that will have an impact on the sufferer's response to treatment.' (Black man affected by cancer, 35–64)

'When my family came to visit me in hospital, they could ask anything to the nurses and doctors and they would help. But outside of hospital, they did not get any support. But I am sure it's because they did not seek it outside of the circle of family and friends. However, it would have been great for help to be offered to my husband at the time when I was in a coma and then recovering from it as he had two small children and me to take care of.'

(Black woman affected by cancer, 18–24)

Some of the BME participants with cancer in the sample chose not to access outside help and to rely on their family and friends instead for support. They were reluctant to talk about cancer. They did not want to 'dwell on the negative', and feared hearing 'frightening' and 'negative' cancer stories from other patients, which would demoralise them.

'In my case, people around me support me by not bringing out the topic of cancer or negative points relating to me or start showing more concerned. This will make me think in a negative way and with wrong thoughts going through the mind.'

(Asian man affected by cancer, 35–64)

'[Sharing with other cancer patients] may open a whole tin of emotional worms.'

(Black woman affected by cancer, 35–64)

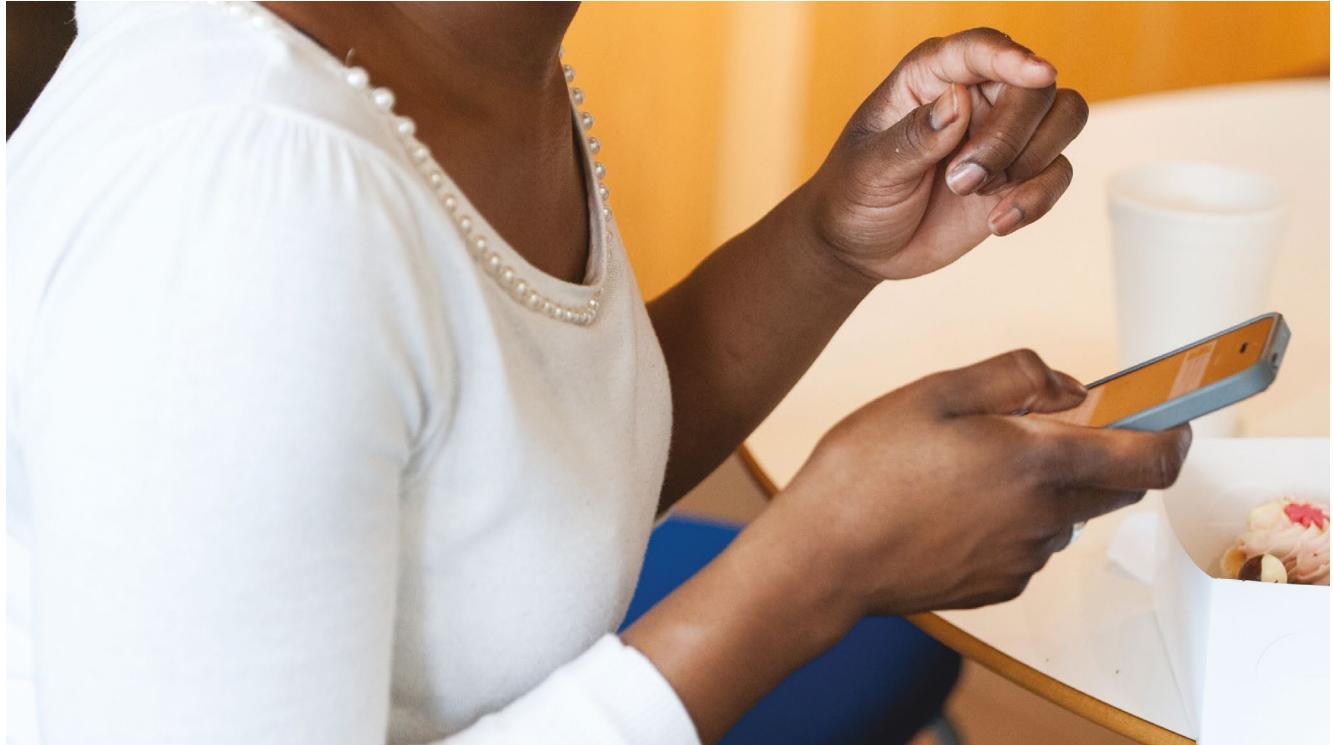
In our sample, the few participants and carers who did attend BME cancer support groups found the experience very positive.

'I am involved in the Asian Women Cancer Support Group... There is reassurance when they see other women who may have been through a cancer journey and come out at the other end. There is an understanding and bonding which becomes very special. We don't just share our experiences. We share recipes, have fun, have social outings together. Members can speak openly and feel easier to talk in the group than to their family members. We understand and help the ladies in empowering them in their life.'

(Health practitioner, Community & Voluntary sector)

'My main carer was my daughter. At the time, there were no advice centres to contact. However, after the set up of our support group, she was involved in and attended the Manchester Cancer Conference as one of the guest speakers, where she met other young carers and cancer survivors. It gave her a chance to address patients and other carers, pose questions and develop a greater understanding of cancer.'

(Asian woman affected by cancer, 35–64)



Post-treatment and survivorship

For most BME participants in the sample (regardless of their demographic profile), cancer does not necessarily end when treatment does. However, this is often the point in the journey where the support needs may seem greatest. This is partly because these needs are the most unexpected (by patients, carers, employers and the wider community) and therefore they are the least catered for. In fact, the participants within our sample said they did not really have time to take stock of the full impact of their cancer until their medical treatment had ended. The reason for this was that until then, they had been intensely dealing with coming to terms with their diagnosis, making practical arrangements during treatments, and focusing on their most pressing physical needs.

'You are just told to go and get on with your life ... I feel scared and abandoned. I would like continued support, just to sit and talk about lifestyle and health choices. I do

belong to a support group and that does help but I would prefer some medical input from a professional ... I feel like I am looking in on life sometimes instead of getting on in the way that I should. I would also like to vent sometimes but am scared to hear myself speak some of the things that are in my head.'
(Black woman affected by cancer, 35–64)

'I'm struggling in that I cannot get my life back to normal. Returning to work has certainly helped as it keeps my mind occupied. We haven't told our children or my family as I don't want them to worry. I just hope that the shadow will decrease in size.'

(Asian woman affected by cancer, 35–64)

'I live every day with the concern about the cancer coming back and the effect it has had on my long-term health, wellbeing and quality of life. I work for myself and things can be really hard. I have no choice but to get on with things.'

(Black woman affected by cancer, 35–64)

b. Physical needs

The Rich Picture: People with cancer from BME groups highlighted a number of physical needs, including:

- Overall, and for many individual cancer sites, people from BME groups are less likely to get cancer than white people. However, there are a few exceptions. Black men are three times more likely to have prostate cancer compared to white men, and death rates from prostate cancer are 30% higher in black men than in white men living in England.^{11, 12} Asian people are between 1.5 and three times more likely to get liver cancer than the white population in England. Black and Asian females aged 65 years and over are at a higher risk of cervical cancer compared to white females in England.¹³ Furthermore, incidences of oral cancer among South Asian people is higher than in any other ethnic group.¹⁴
- Participants in clinical cancer trials have better outcomes than are reported in the population at large, but people from BME groups are less likely to participate.¹⁵
- Evidence regarding ethnicity and uptake of follow-up surveillance found that cancer survivors from white communities were more likely to receive follow-up than survivors from BME communities.¹⁶

Accessing treatment

In our sample, some BME participants reported difficulties in accessing treatment at some point in the cancer journey, or of being unsure as to whether or not they should be receiving a particular treatment.

'We had to push for the first consultation, despite leaving messages on the only contact number I had. We also had to push to arrange a date for the operation. The consultant's manner was quite curt and I did not feel comfortable about asking any questions regarding the operation and post surgery care. The only advice I had related to breathing exercises.'
(Asian woman affected by cancer, 35-64)

'I always feel as if I am bothering someone. Like they know of a reason that I should not worry and are looking at me as if I am neurotic. I know it's an irrational fear, but that fear came from having cancer so it's really a horrid Catch 22. I don't know why I am not getting treatment. Everything seemed to be a question rather than a definitive statement. Perhaps we'll give you radiotherapy, we'll discuss at a later date. Perhaps you'll need another surgery, we'll discuss at a later date. Perhaps we'll have to drain the blood from your face, we'll discuss at a later date. As none of those things were discussed at a later date, I never quite felt sure where I stood.'
(Black woman affected by cancer, 35-64)

The only cases of delays directly and specifically linked to ethnicity mentioned in our sample were difficulties in securing bone marrow for transplantation, and a longer wait for a prostheses that matched skin colour. One Black Caribbean participant reported that she was very lucky that her sister could be a bone marrow donor. However, a Black African participant had been unable to find a bone marrow donor for eight years, despite national and international searches, because too few people from BME communities are donors.¹⁷

'The only cure for myelofibrosis is bone marrow transplant, but no match has been found for me yet due to the low numbers of black people in the bone marrow register.'
(Black man affected by cancer, 35–64)

Post-treatment

The BME participants in our sample reported poor experiences at the end of their treatment. They were less likely to have received treatment summaries. They were less likely to have had an in-depth discussion about their needs and the support that was available to them on discharge. They were less likely to have been advised about the signs and symptoms to look out for. They were also less likely to have received regular specialist follow-ups and to have been helped with the long-term physical and emotional impact of cancer and its treatments.

'I had no aftercare plan or needs assessment. I did not have a key worker and would contact my GP if I have any concerns. I am followed for bowel cancer. I am very concerned about the cancer coming back – the scan after the final treatment showed a shadow between the two lungs and I will have another scan in three months' time. If the shadow has got bigger, I will need a PET scan and will require either surgery or radiotherapy. I have also lost my sexual appetite. I'm struggling in that I cannot get my life back to normal. Returning to work has certainly helped as it keeps my mind occupied. We haven't told our children or my family as I don't want them to worry. I just hope that the shadow will decrease in size.'
(Asian woman affected by cancer, 35–64)

'After treatment (surgery), there was no discussion of long-term plans apart from the usual visits to ENT. I wish I had had a treatment summary. I am planning on asking for a copy of my medical records very soon. I know who to contact. I don't feel 100% comfortable to get in contact but I will if I am too concerned about something. I feel that I know what to look for but that medical professionals want to belittle what you should be aware of. I live every day with the concern about the cancer coming back and the effect it has had on my long-term health, wellbeing and quality of life. I work for myself and things can be really hard. I have no choice but to get on with things. In an ideal world, my medical worries would be eased and my financial concerns understood.'

(Black woman affected by cancer, 35–64)

Comorbidities and impact on health

The frustrations and difficulties with not being cared for in a person-centred way were understandably most acute for those with multiple needs or comorbidities (including pre-existing chronic conditions). This could sometimes lead the participant to develop further comorbidities.

'I don't feel that I was ever treated as a whole person. I have severe endometriosis and a pituitary adenoma, as well as other health complications. I had these before the cancer. Both of these conditions caused issues that were being treated at the time of my cancer diagnosis. The ENT oncologist treated me for the cancer.'



The gynecologist treats me for my endo. The endocrine specialist treats me for my pit tumour. None took into consideration any of the other conditions and how they might affect treatment. Each specialist has their area of expertise and they deal only with that. The GP will only deal with one problem at a time. However, my body doesn't deal with only one problem at a time, nor do my symptoms differentiate between which doctor I am seeing. It would be great to be seen by someone who can look at me as a whole person and then treat me accordingly.'

(Black woman affected by cancer, 35–64)

Indeed, the participants living with cancer in our sample discussed at length the impact cancer had on their self-confidence and sense of agency, their relationships, family and social life, and their work and financial situation.

'I always have to be around a toilet facility wherever I go. I have found intimacy difficult after

cancer and have not looked for new relationships. I try to keep fit within my capabilities but have limitations due to chronic back problems, abdominal hernia and an inadequate ileostomy that easily gets dislodged. I have grown spiritually, learned to accept my situation, but haven't conquered anxiety about future. I find it difficult to concentrate for a long period so I don't read as much as I used to. I had a career and was set to be at the top when I was diagnosed with cancer. I had hoped to return to work but it was not possible. I enjoyed my work and missed it initially when I decided to retire. I took a big drop in my finance when I retired but am comfortable. My family and friends were there for me in my hour of need. I have got to know my local community due to my fundraising and awareness-raising activities. I love traveling and continue to do so, but can no longer go to 'way out' places. I can't be spontaneous.'

(Asian woman affected by cancer, 35–64)

c. Practical needs

The Rich Picture: People with cancer from BME groups highlighted a number of practical needs, including:

- 83% of all people are affected financially by a cancer diagnosis, however, the financial impact may be starker for people from BME groups.¹⁸ This is because some experience higher rates of poverty. Around 40% of black, Asian and other ethnic groups, and 35% of mixed ethnic groups live in low-income households, compared with less than 20% of the white population.¹⁹
- Poor communication between healthcare professionals and the patient is often reported when people from BME communities are at the end of life care stage of their cancer journey.²⁰
- Cancer awareness and help-seeking behaviours among people from BME groups are low across all ethnic groups.²¹

Finances

The financial impact of cancer was manifest within our sample in different ways. First and foremost, cancer led to significant drops in income. It forced our participants into leaving their work, taking early retirement (and a reduced pension), cutting down on their hours, changing careers or fields of study for less demanding ones, moving in (or remaining with) their family to save on housing costs, carrying on working when they should have been resting, or returning to work earlier than would be desirable on clinical grounds. In our sample, eight participants lived with their parents and/or their siblings.

Despite everyone being of working age, only seven were working full-time (sometimes in self-employment). Six worked part-time, three were not working for medical reasons, two had taken early retirement following their cancer, and one was unemployed.

'I cannot do overtime anymore.'

(Black man affected by cancer, 35–64)

'I started working for myself before I was diagnosed so my income and career were hugely affected. I am still plodding along, but the things I would have achieved have taken much, much longer to accomplish. Working for myself and being unwell mean that I can only work when I am well enough.'

(Black woman affected by cancer, 35–64)

'I had to change career paths, which was depressing at the time. I gave up studying Law.'

(Black woman affected by cancer, 18–24)

Cancer also led to increases in expenditure. Much like for other cancer patients, the main additional expenses for our participants were linked to the cost of traveling to appointments, car parking and heating costs. Those with dependent children sometimes had to make childcare arrangements. To minimise expenditure, one participant, for instance, used public transport when it was unsafe for her to do so, leading to infections and delays in treatment.

Impact of Clinical Nurse Specialists

The research did not systematically explore whether the BME participants with cancer had access to a Clinical Nurse Specialist (CNS). Very few spontaneously mentioned that they had access to a CNS but, for those who did, this was a key driver of satisfaction with

cancer services. In particular, it seemed to help with navigation across the NHS, with answering questions and with accessing additional services.

'Whilst talking to some of the other cancer patients, I realised that they all had specialist nurses they could call on for advice. It would have been really helpful if this facility had been made available to me.'

(Asian woman affected by cancer, 35–64)

'My Clinical Nurse Specialist was my 'go to' lady. She put me in touch with my counsellor and the Macmillan team. They all pointed me to the right directions.'

(Black woman affected by cancer, 18–24)

Information

Some of the BME participants in our sample wanted information to restore a sense of control in a situation where they felt powerless and vulnerable. They were extremely active in seeking information, read every leaflet they were given, searched various specialist websites, posted specific questions on forums, etc.

'I was only given basic information about the surgery – a hospital leaflet explaining the procedure. All the other information I found from Cancer Research UK's website, Macmillan Cancer Support's website, Bowel Cancer UK and Beating Bowel Cancer's website. I use the internet a lot. For specific questions, I have posted on forums and got good advice from fellow cancer patients. It would have been nice to have a list given to you at the time of diagnosis so you or your family can research, ask relevant questions and look at options.'

(Asian woman affected by cancer, 35–64)

Conversely, those who felt they had too much information were typically less confident about accessing and deciphering complex health information. They were often emotionally overwhelmed by their diagnosis and feared learning about cancer. They preferred not to seek out any information beyond that given to them by healthcare professionals.

'I followed advice that I was given without question, since I felt that they knew better than me, and I would never have relied on myself to challenge anything I was told through fear of 'jinxing' my recovery. I purposely did not seek out too much information as it would have scared me too much.'

(Black woman affected by cancer, 35–64)

'Having prostate cancer, I was not given much information or if information was given to me, it did not make sense to me. There were things said to me about considering taking this drug or that drug, but when I asked if these drugs would make me better, there was always a pause, then I would hear about the side effects these drugs would give me.'

(Black man affected by cancer, 18–34)

This last quote above, in particular, points to the challenges of getting the information right. This participant wanted to know that his prostate treatment would make him better; in response, he was told of the negative side effects each treatment option could have.

The healthcare professionals, diversity specialists and academics in our sample often commented on the need for written information to be simple, clear, with short and non-technical messages and pictorial information.



While they recognised that written information on cancer should be available in various minority languages, there was a consensus that the mere translation of written information devised for the majority white British population would not suffice.

'There is quite a bit of written information around for BME communities in minority languages but it still fails to have much impact and providers need to ask the question, 'Why?' What is needed is services for the community by the community ... Providers are always looking for easy answer – ie, "Let's translate", when the reality is that a lot of elderly BME people can't read in their own language, so a lot of leaflets are just binned. It is better to go out and talk to people in their own environments or help set up support or information groups.'
(Health practitioner, Community & Voluntary sector)

'The obsession with language barriers needs to be put to rest! Yes, there are language barriers

and they must be overcome, but this affects a relatively small number of BME people.'
(Academic/researcher)

Our sample of BME participants living with cancer generally wanted less technical, more personalised information, presented proactively. More specifically, they wanted to understand their diagnosis and prognosis (including why they got cancer, and some explicit reassurance that cancer is not always a death sentence).

'I would like the doctor who breaks the news to me to be the same person who gives me more information about it. That person holds a lot of power because we trust what they say for the most part, so if they were to say, "Go here for more info," or, "It has this chance of survival," it is real. That information is precious and how it relates to us individually, more so. When they give us those details, we can then ask, "What does that mean for me?"'

(Black woman affected by cancer, 35–64)

They were especially interested in the consequences of their cancer and cancer treatment for themselves and their loved ones, and they wanted help on how to tell others (their spouses, children and parents) about their diagnosis and prognosis.

'I just wanted facts and the most asked questions and how cancer would have been affecting my daily living and that of my family. Also not every hospital has support for those who are supporting us and that is the biggest issue, keeping them informed.'

(Black woman affected by cancer, 18–24)

'I would have liked more support in how people may react ... and how much information to tell friends and relatives specifically about my cancer.'

(Black woman affected by cancer, 35–64)

They wanted clear, but simple, information on their treatment options and the associated consequences, both in the short term and the long term. This included information on the side effects of treatments (eg, fatigue, hair loss, weight loss or weight gain). It also included practical information on how to cope with the impact of cancer and cancer treatment (eg, contact details of key staff, relevant websites, financial help, community transport, maps of parking at hospitals, access to suitable wigs, dietary advice, recommended physical activities, alternative therapies, massages, access to counseling, etc). Some participants in the sample also requested information on why they were not offered certain treatments, to reassure themselves that all options had been considered and that they were not missing out on the best treatment.

'I also got information from the patient liaison staff in the hospital on how to complete the disability claim forms, which was of great help to me.'

(Black man affected by cancer, 35–64)

Having access to information and being able to have an open and informed conversation with doctors about treatment options based on an assessment of their specific health conditions, lifestyle, needs and priorities, were essential to feeling in control. This was not only empowering and emotionally supportive; it could lead to different treatment decisions and life outcomes for the participant. Participants who experienced this degree of respect for their choice – having been made aware of the risks and benefits of each option – were extremely positive.

'Against the advice of the doctors, I got pregnant twice and gave birth to two girls in a space of 11 months whilst having leukaemia. But I followed my instinct and they supported me, and they got me to delivery day safe and sound. Amazing people. Thank God for the NHS.'

(Black woman affected by cancer, 18–34)

'As my first cancer is not very common – one in 100,000 – doctors took time to explain in more detail the course of action, and what I wanted. I was able to take part in decision-making along the way, which made me feel that I am taking an active part in my treatment and also gave me a bit of ownership'

(Black man affected by cancer, 35–64)

d. Underlying assumptions and perceptions

The Rich Picture: People with cancer from BME groups highlighted a number of underlying assumptions and perceptions, including:

- People from BME groups are less likely to participate in clinical cancer trials. Some of the barriers to participation include cultural factors such as fear and cancer stigma, and mistrust of the medical system.²²
- Some BME groups have a strong reliance on spiritual belief and practice – this can have important implications for the way that they want to be cared for at the end of life.²³

Impact of stigma around cancer

BME participants within our sample reported a lack of ease, ability or willingness to discuss their cancer with others due to the existence of stigma about cancer in their community. They told of how they were met with unsympathetic responses when they disclosed their condition.

'If anyone tries to bring out the topic [of cancer], then I immediately switch the topic ... I just don't give them the chance to elaborate further and that is full stop. If they continue, then I will tell them, "Don't we have something else that we can talk about? Why talk about this boring subject? We have come here to enjoy, so forget about the problem." I don't get entangled in this conversation.'

(Asian man affected by cancer, 35–64)

'I did not have family support ... Currently in our group, we find that

some husbands are unable to cope with their partner's condition in terms of diagnosis, feelings, body change, etc. This is particularly the older group around 55 plus.'

(Asian woman affected by cancer, 35–64)

The BME participants living with and affected by cancer in our sample were deeply concerned about minimising the negative impact of their cancer on those who love them and care for them. They did not consider their family members as 'carers' (the word is associated with paid employment, not love and care freely given by family members). They would therefore not request support for 'carers', but they were extremely worried about the additional burden of care that their cancer imposed on their loved ones.

Within the sample, participants, healthcare professionals, diversity specialists and academics all reported that BME communities are much less aware than other groups about various aspects of cancer. These include what cancer is, the warning signs of cancer, the lifestyle factors that increase or reduce the risk of cancer, and of the importance of early detection and screening. This is consistent with existing evidence.²⁴ Most BME participants discussed how they knew very little at all about cancer at the time of their diagnosis.

'I never knew anything at all about cancer at that point. My steep learning curve was about to start.'

(Black woman affected by cancer, 35–64)

'I was told along with my parents and none of us knew what cancer was, let alone leukaemia.'

(Black woman affected by cancer, 18–34)

Some within the sample argued that awareness and knowledge among BME communities are much lower in relation to cancer specifically than for many other conditions. For instance:

'Asians now are well aware of health issues such as diabetes, overweight and obesity, heart disease, stroke and hypertension, etc, but I don't think there is the same level of awareness and talk about cancer at all.'

(Academic/researcher)

Misconceptions

At the point of diagnosis, participants were more likely to report that they thought they would die and that there was little medicine could do to prevent this. They preferred not to use the word 'cancer' themselves, and reported significant difficulties in communicating their diagnosis to others.

'I say I was diagnosed with lymphoma, still undergoing treatment. That's the closest I get to identifying myself with the disease. My experience hasn't been widely shared within my community ...'

(Black woman affected by cancer, 18–34)

'I prefer to say that I have myelofibrosis and prostate illness. The word cancer draws a bad picture in my mind of someone dying soon.'

(Black man affected by cancer, 35–64)

In our sample, almost half of the BME participants thought that most cancers are inherited. These types of misconceptions can make it difficult for BME communities in general, and cancer patients in particular, to talk and learn about cancer, to think that cancer is relevant to them,

to engage in preventive action, and to take action to detect cancer early²⁵. Such misconceptions can also influence treatment decisions and have implications for help-seeking behaviours throughout the entire journey.

End of life

There was a strong reluctance to talk about death, dying and preparing for the end of life among the participants with cancer in our sample. Only 11 participants answered this question at all – often simply to state that they did not wish to think about the meaning of dying well.

'I am a very positive person and have not thought about the end of life and therefore cannot comment.'

(Asian woman affected by cancer, 35–64)

'Sorry I generally can't answer this question ...'

(Black woman affected by cancer, 18–34)

'A good friend of mine died of breast cancer in September. I saw her through those last painful weeks, making decisions for the end of her life. It was so painful to see her go through that process because she really wanted more time. I can't contemplate thinking of this because I feel VERY determined to be here.'

(Asian woman affected by cancer, 35–64)

'I have an active mind and can easily take myself into thoughts that I feel would not be productive for me right now.'

(Black woman affected by cancer, 18–34)

This silence strongly suggests that there are unmet needs in terms of BME patients and their families being supported in properly planning for the end of their lives in a way that acknowledges the depth and breadth of their needs and preferences, and includes all relevant parties in an open, positive discussion. Indeed, only one BME participant (who had worked in the NHS) mentioned having made basic arrangements and discussed death with her family.

'I have discussed my wishes with my family. I want to have quality of life not quantity. I have made them aware about DNR. I do not want to be in pain or suffer.'

(Asian woman affected by cancer, 35–64)

The only participant who gave a substantive answer to the question of what 'dying well' would mean to him spoke of the need to die with dignity, without pain and with active treatment until the end. There seemed to be a latent fear that BME cancer patients could be refused costly treatment and care.

'To me, it means dying with dignity, without pains or suffering. It means the person suffering with cancer should be treated with all the care that would be given to any other, right from the beginning, including medical, no matter how much it cost to the NHS. After all, we are paying and we should have this fundamental right to live with dignity and not being treated differently because the doctors and nurses know soon there will be an end to us. We should have all the right to have the best of the treatment and not being refused or delayed and for which we may have more pain and suffering or being

pushed to the corner as if we are not wanted. If we are treated and given the medication (no matter what is the cost), then I will die with dignity and not die because I was a burden to other or NHS.'

(Asian man affected by cancer, 35–64)

The evidence from this project is minimal in relation to palliative care and end of life, but it is consistent with the existing literature on BME needs summarised in research carried out for Marie Curie Cancer Care.²⁶

Assumptions and stereotypes

Most BME participants in the sample did not think healthcare professionals had ever discriminated against them personally. Patients' assessments of fairness or discrimination were exclusively based on personal interactions with staff. For instance:

'I was not patronised. No assumptions were made about me because of my ethnic origin. The nursing staff who nursed me ranged from exceptional to bad – 'bad' meaning lacking skills rather than being prejudiced. Though information was sometimes not volunteered, it was given if asked.'

(Asian woman affected by cancer, 35–64)

'I was not aware at the time of any groups coming together to provide emotional support and personal wellbeing for Asian women cancer patients ... I wouldn't regard it as being treated unfairly, but perhaps a lack of awareness?'

(Asian woman affected by cancer, 35–64)

However, some BME participants in the sample reported discrimination and perceived that healthcare providers at times relied on assumptions and

stereotypes in their interactions, instead of treating them as individuals while being informed of the ways in which the socio-demographic characteristics can impact on cancer rates, cancer experiences and cancer-related needs.

**'Having worked in the NHS,
I have come across staff who
make assumptions about people
because they come from different
backgrounds, talk loudly to
explain when there are language
issues, make faces or ignore them
altogether.'**

(Asian woman affected by cancer, 35–64)



WHAT MACMILLAN WANTS TO DO

We know that this is only part of a much bigger story around the experiences of BME people living with and affected by cancer.

In order for this work to continue to explore and understand the needs of BME people with cancer, Macmillan wants to:

- work with BME people living with and affected by cancer, using their experience to identify health inequalities and variation in experience. Together, we aim to co-design solutions, and influence decision-makers at local, regional, and national levels to tackle health inequalities.
- work with multiple partners and stakeholders within the BME community to develop and strengthen our knowledge around the experiences of those within the BME community who are living with and affected by cancer.
- provide support for BME people living with and affected by cancer to develop their skills, resources and confidence to self-organise and use their experiences to influence decision-makers.

WHAT CAN I DO?

This report provides a lot of food for thought, and we hope that it is just the start of the conversation. With this in mind, we would like to invite BME people living with and affected by cancer – as well as health and social care professionals – to join a BME taskforce. This taskforce will aim to produce recommendations arising from this report, prioritise the issues that the members want to address, and co-design and prototype solutions.

If you would like to get involved and help shape the future of cancer care for people from the BME community, please contact us at researchlearning@macmillan.org.uk

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Appendix

Below is an overview of the engagement exercises that participants took part in.

Final Task Plan

Macmillan research into inequalities in experiences of cancer services

WEEK	TASK TITLES	ALLOCATION	RESPONSES
Wk 1.1. Wk 1.2. Wk 1.3. Wk 1.4. Wk 1.5. Wk 1.6. Wk 1.7.	Getting to know you Your needs and expectations of this community How did you hear about us? Overview of your cancer Thinking about cancer Getting the language right The Wheel of Life	All participants All participants All participants PLWC only All participants All participants All participants PLWC only	Open Open In private In segment In segment In segment In segment In private
Wk 2.1 Wk 2.2 Wk 2.3. Wk 2.4.	I am ... A picture is worth a thousand words Your body Take a peek and share	PLWC only PLWC only PLWC only PLWC and Professionals	In private Open In private In segment
Week 2.1.	Life at work	Professionals only	In segment
Week 2.2.	A picture is worth a thousand words	Professionals only	In segment
Week 2.3.	Working on health and equality	Professionals only	Open
Week 2.4.	Case study: Sam	Professionals only	Open
Wk 3.1. Wk 3.2. Wk 3.3. Wk 3.4. Wk 3.5.	Dear Diary ... Tips to doctors Your initial reaction Timing can make a big difference Navigating the system	PLWC only PLWC only PLWC only PLWC only PLWC only	In private In segment In segment In segment In segment
Week 3.1.	Breaking the news	Professionals only	Open
Week 3.2.	Late presentation and diagnosis	Professionals only	Open
Week 3.3.	Late treatment	Professionals only	Open
Week 3.4.	Case study: Omar	Professionals only	Open
Wk 4.1. Wk 4.2. Wk 4.3. Wk 4.4. Wk 4.5. Wk 4.6. Wk 4.7.	Holistic approach to individual needs Information and resources for patients Involvement in decisions about care: survey Involvement in decisions about care: survey Involvement in decisions about care: blog Thinking about the end of life Thank goodness ...	PLWC only PLWC only PLWC only PLWC only PLWC only PLWC only PLWC only	In segment In segment In private In private In segment In segment In segment
Week 4.1.	Holistic approach to individual needs	Professionals only	In segment
Week 4.2.	Information and resources for patients	Professionals only	In segment
Week 4.3.	Involvement in decisions about care	Professionals only	In segment
Week 4.4.	Case study: Susan	Professionals only	In segment

WEEK	TASK TITLES	ALLOCATION	RESPONSES
Wk 5.1. Wk 5.2. Wk 5.3. Wk 5.4. Wk 5.5. Wk 5.6. Wk 5.7.	The impact of cancer on people around you Support for people who care about you Adjusting to life once treatment is over Being active in the community Then and now On balance, I feel ... Bin it!	PLWC only PLWC only PLWC only PLWC only PLWC only PLWC only PLWC only	In segment In segment In segment In private In segment In private In segment
Week 5.1.	The impact of cancer on people around older cancer patients	Professionals only	In segment
Week 5.2.	Support for people who care for cancer patients	Professionals only	In segment
Week 5.3.	Adjusting to life once treatment is over	Professionals only	In segment
Week 5.4.	Being active in the community	Professionals only	In segment
Wk 6.1. Wk 6.2.	Should 'equality' matter? Discrimination based on age a) What else could explain poorer experiences or outcomes? b) What else could explain poorer experiences or outcomes? c) What else could explain poorer experiences or outcomes?	PLWC only PLWC and Professionals	In segment In segment
Wk 6.3.	Your public health campaign	PLWC only	Open
Wk 6.4.	Why do perceived inequalities exist? Managing difficult situations	Professionals only Professionals only	In segment In segment
Wk 6.5.	Your public health campaign	Professionals only	Open
Wk 7.1. Wk 7.2. Wk 7.3. Wk 7.4. Wk 7.5. Wk 7.6. Week 7.3.	Your shout Top three lessons A cup of tea with your doctor Message in a bottle I pledge ... The last word Professional engagement and capacity building	PLWC and Professionals PLWC and Professionals PLWC only PLWC and Professionals PLWC and Professionals PLWC and Professionals Professionals only	Open Open In segment In segment In private Open Open

'Open' means that all participants assigned this activity can see and comment on other participants' posts.

'In segment' means that if participants share a segment, they can see and comment on other participants' posts.

'In private' means that no one apart from the posting participant can see the answer. Some tasks can ONLY be set as private (such as 'Mark Up' tasks or surveys).

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. Whether it's concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we're here. Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support, giving you the energy and inspiration to help you take back control of your life.

For support, information or if you just want to chat, call us free
on **0808 808 00 00** (Monday to Friday, 9am–8pm)
or visit macmillan.org.uk