

Cancer
equals



1,000 voices,
not 1

A Report Highlighting Differences
in Cancer Care in the UK

Developed by



In partnership with



This non-promotional campaign has been fully funded and developed by Bristol Myers Squibb.

FOREWORD

We must confront a stark reality.

Cancer is the leading cause of death worldwide.¹ In the UK, more than two million years of life are lost to cancer each year.²

As people living with cancer in the UK, we have experienced firsthand the physical, psychological, and financial toll this disease can take. But our four stories are all very different.

No two people will experience cancer in the same way. There are countless factors that impact a person's experience of the disease and ultimately their outcome. Where a person lives, their ethnicity, education, age, and gender are all factors that can contribute to when and how they might be diagnosed with cancer and their access to care.

"Cancer Equals" aims to tell the real-life stories of people impacted by cancer. People just like us.

This research report highlights some of the challenges that people living with cancer are facing and the inequalities that exist in how cancer is experienced across the UK. We see a lot of our stories in this report, and echo many of its findings. It is personal to us, and we want to see change.

We ask that all those reading this report recognise that these inequalities are avoidable and that there is a need for change.

By sharing our stories, we hope to encourage other people living with cancer to come forward and talk about their experiences. Together with Bristol Myers Squibb and Shine Cancer Support, we hope to bring people together to better understand the causes of cancer inequalities and the impact they are having. Our goal is to find solutions. This report is just the first step.

We are **1,000 voices, not 1**. Together, we can make a difference.



Simeon

Diagnosed with prostate cancer at age 49.
Lives in Wolverhampton



Precious

Diagnosed with chronic myeloid leukaemia at age 33.
Lives in North London



Alice

Diagnosed with bowel cancer at age 42.
Lives in West Sussex



Belinda

Diagnosed with stomach cancer at age 66.
Lives in Shropshire

1. WHO. Cancer Key Facts. <https://www.who.int/news-room/fact-sheets/detail/cancer> Accessed April 2024. 2. BJC. Years of life lost due to cancer in the United Kingdom from 1988 to 2017. <https://www.nature.com/articles/s41416-023-02422-8>. Accessed April 2024

Cancer equals

Highlighting Differences
in Cancer Care in the UK

Bristol Myers Squibb launched the *Cancer Equals* campaign to understand and address the many factors that lead to unacceptable delays in cancer diagnosis and variations in cancer experiences between people from different backgrounds in the UK.

By understanding the true impact inequalities have on people, *Cancer Equals* aims to develop and implement strategies to address the issues identified.

For more information on *Cancer Equals*, go to:

cancerequals.co.uk

To form the foundations of this campaign, Bristol Myers Squibb carried out quantitative and qualitative research in partnership with Shine Cancer Support.

The **1,000 voices, not 1** report has been developed from this research and tells the real-life stories of people living with cancer, highlighting inequalities within their experiences.



|| *This report and the wider Cancer Equals campaign bring to light the voices of real people who have experienced varying inequalities whilst going through their cancer journey. Through the campaign, we aim to create a nation-wide conversation and support the development of solutions that tackle health inequalities in cancer in the UK. ||*

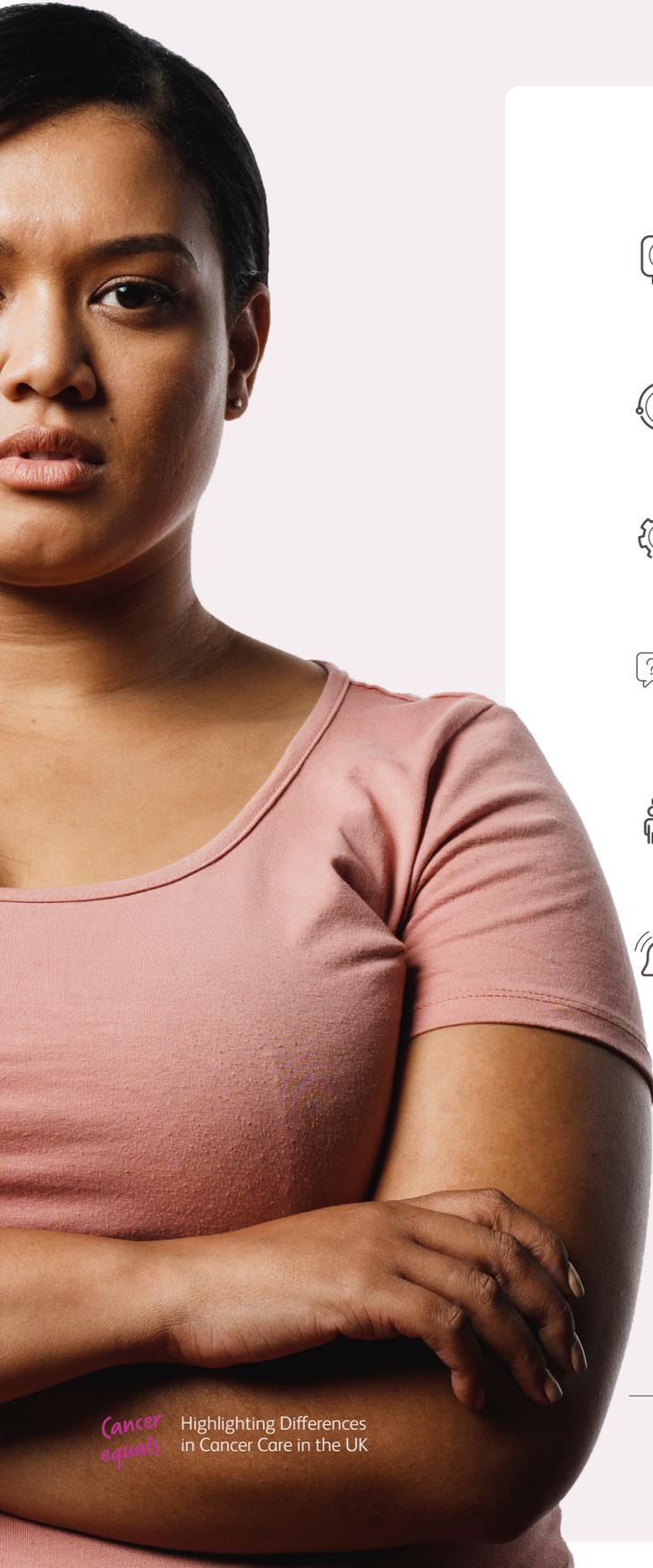
Dr Robert Braun, Haematology-Oncology Disease Area
Head, Bristol Myers Squibb UK & Ireland

|| *This is an important discussion to have with as many people as possible, to spread awareness and maximise the number of cancers identified through screening in their early stages, when they are at their most treatable. ||*

Ceinwen Giles, Shine Cancer Support

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START the conversation on
inequalities in cancer.



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WHAT are health inequalities and why do they exist in cancer?

In the UK, considerable strides have been made in improving outcomes for people impacted by cancer, with survival rates doubling over the last 50 years as treatment and diagnostic services have improved.¹

However, cancer outcomes are influenced by more than scientific innovation. Inequalities across a number of environmental and social factors play a key role in late diagnosis, a key driver for poor cancer outcomes.²

Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society.³ They play a fundamental role in cancer incidence and outcomes across populations.^{2,3}

A report by Cancer Research UK in 2020 estimated that across the UK, more than 30,000 cases of cancer are attributable to socioeconomic deprivation.⁴ That's equivalent to more than 80 diagnoses per day which could be avoided.

People in areas of deprivation not only have a higher cancer risk, but can face barriers to seeking early support. Barriers include failures to bring awareness of cancer symptoms, lack of support, geographical or language constraints, lower uptake of screening, and access to information.⁴⁻⁶

People from minority ethnic groups report more negative experiences of cancer care than white people, limited cancer education, and awareness of support services.⁷

The overall impact is later diagnosis and poorer outcomes for the UK's most deprived populations compared with the least deprived.⁴

Global data suggests that every month delayed between cancer diagnosis and treatment may raise the risk of death by around 10%.⁸ Therefore, earlier diagnosis and reduced delays to treatment could improve cancer survival rates.

1. CRUK. Cancer Survival Statistics. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival>. Accessed April 2024. 2. Ashley, L., and Lawrie, I. (2016) *Tackling inequalities in cancer care and outcomes: psychosocial mechanisms and targets for change*. *Psycho-Oncology*, 25: 1122–1126. doi: 10.1002/pon.4278. 3. NHS England, What are healthcare inequalities. <https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/>. Accessed April 2024. 4. CRUK. Cancer in the UK 2020: socio-economic deprivation. https://www.cancerresearchuk.org/sites/default/files/cancer_inequalities_in_the_uk.pdf. Accessed April 2024. 5. Niksic, M; Rachet, B; Warburton, FG; Wardle, J; Ramirez, AJ; Forbes, LJJ; (2015) *Cancer symptom awareness and barriers to symptomatic presentation in England--are we clear on cancer?* *British journal of cancer*, 113 (3). pp. 533-542. ISSN 0007-0920 DOI: <https://doi.org/10.1038/bjc.2015.164> 6. Niksic M, Rachet B, Duffy SW, Quaresma M, Møller H, Forbes LJ. *Is cancer survival associated with cancer symptom awareness and barriers to seeking medical help in England? An ecological study*. *Br J Cancer*. 2016 Sep 27;115(7):876-86. doi: 10.1038/bjc.2016.246. Epub 2016 Aug 18. PMID: 27537388; PMCID: PMC5046204. 7. Racial Equity Foundation. *Cancer and Black and minority ethnic communities*. <https://raceequalityfoundation.org.uk/health-and-care/cancer-and-black-and-minority-ethnic-communities/>. Accessed April 2024 8. Hanna, T.P. et al. (2020) *'Mortality due to cancer treatment delay: Systematic review and meta-analysis'*, *BMJ*, m4087. doi:10.1136/bmj.m4087.





METHODOLOGY

Bristol Myers Squibb, in partnership with Shine Cancer Support, commissioned UK-wide research to better understand the drivers and causes of inequality in cancer care.

The research was conducted over two stages

1 - Qualitative Research

In-depth interviews were carried out to gather rich, anecdotal insights into the real-life experiences of over 30 people living with cancer in the UK who present with...



Various cancers



Mix of ages and genders



Mix of ethnicities

The qualitative research was conducted in two phases, between September 2022 and November 2022, and between August 2023 and March 2024

2 - Quantitative Research

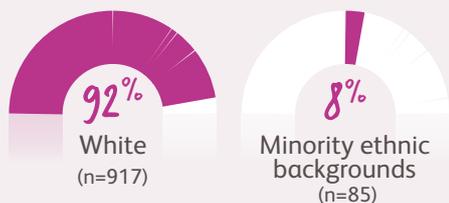
A survey was distributed by YouGov and Shine Cancer Support to 1,002 people living with cancer in the UK, which provided detail into the common environmental and social factors that contribute to UK cancer outcomes.

Respondents were from all four UK nations

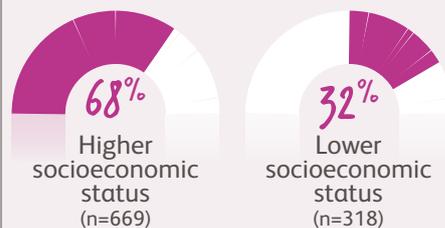
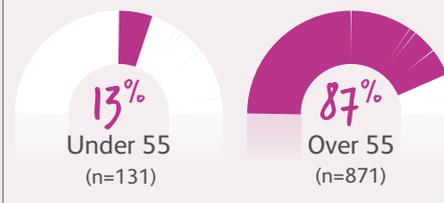


Socioeconomic status was determined as either **ABC1** (higher socioeconomic status) or **C2DE** (lower socioeconomic status) using location, income, education, upbringing, and housing & benefits.

Ethnicity was categorised as



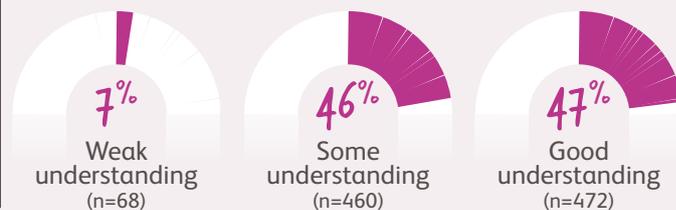
Age was categorised as either



Household income was categorised as either



Understanding of cancer was categorised as

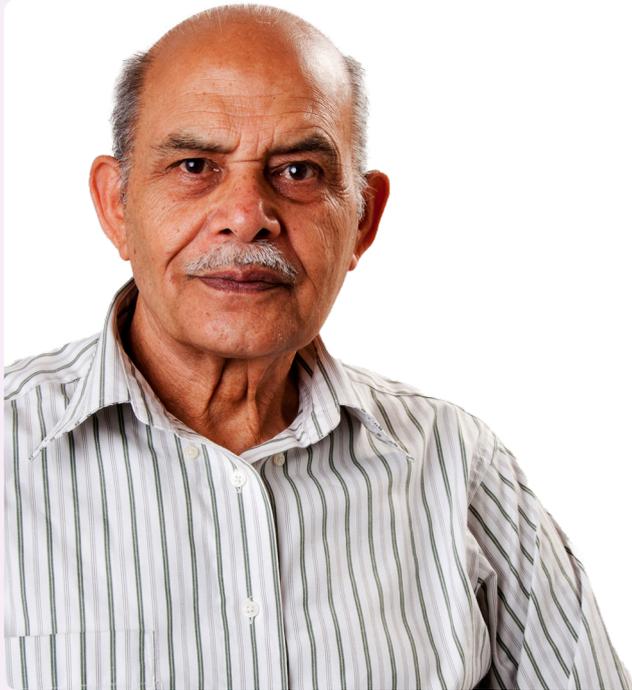


The quantitative research was conducted between December 2022 and June 2023.



WHAT do inequalities in cancer look like?

Inequalities in cancer are visible at all stages of the condition – before and after diagnosis.



Before diagnosis

Time from symptom onset to diagnosis was

7 months longer

for people from minority ethnic (n=85) groups compared with white patients (n=917)

11.9 months Vs **4.9 months**

The survey suggests that drivers of diagnostic delays could include...

Low awareness of cancer and associated symptoms

People from minority ethnic groups were significantly more likely to not take their symptoms seriously compared with white people

Challenges accessing services

People from minority ethnic groups were significantly more likely to not want to be seen as wasting their GP's time compared with white people

Proportion of people who agreed with:

"I did not take my symptoms seriously"



"I did not want to be seen as wasting my GPs time"



Minority Ethnic   White



Socioeconomic status was found to impact a person's understanding of cancer and their likelihood of seeking a diagnosis...

Proportion of people who agreed with:

"I had heard about cancer and had a good understanding of the disease"



Which was found to impact the subsequent number of appointments a person may have before diagnosis

Patients with a weak understanding of cancer prior to diagnosis were significantly more likely to need 2-3 appointments before referral, compared with those who reported a good understanding of cancer before diagnosis



|| I wasn't aware of stomach cancer. I'd not even heard of it. You hear about lung cancer or tumours but stomach cancer, I had never heard of that before. Until I actually got diagnosed with it. ||
Belinda



|| Cancer wasn't on my mind. When I first went to the GP, I had all the symptoms, I didn't know what they were, and I couldn't link them because I had no idea they were related. And I remember going to the GP several times. ||
Precious





Knowledge of cancer is lower in people from minority ethnic groups

Reported misconceptions about cancer

Proportion of people who agreed with:

"I thought my symptoms were related to other diseases/conditions"

"Cancer is a death sentence"

"Cancer treatment is worse than cancer itself"



|| When we were younger you didn't say the word cancer, it was the 'big C'. You never mentioned the word cancer because if you had cancer, it was believed you were basically going to die. ||
Anonymous respondent





People's perceptions of cancer are linked to their exposure to the condition

Sources shaping peoples' impressions of cancer pre-diagnosis include:



Cancer is often seen as 'something that happens to someone else'

|| An advert that I saw at the time said if you feel a lump, go to your GP. I never saw anything that said if you had discharge or inverted nipples go to the GP. Because I didn't feel a lump I didn't know I needed checking out. **||**

Anonymous respondent

|| We always say that people have to be older when they get cancer. I think when you're like me, a busy, almost middle-aged mum trying to do everything at once, it's never in your mind that it's something that could happen to you. **||**

Alice

|| I went from not knowing anyone who had cancer to having a cancer diagnosis myself. I didn't have a reference point. All I knew was if people have cancer, they died. **||** Precious



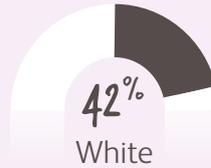


Barriers to healthcare-seeking behaviour

People don't want to cause a 'fuss' and are highly deferent to the health system, but there are also challenges to attending appointments.

Proportion of people who **agreed** with:

"When interacting with the NHS, I often worry about wasting their time and resources"



"Lower socio-economic groups are also more likely to deal with health issues on their own and not bother a doctor"



"I wasn't very good with doing doctor's appointments and things, I think I probably had quite a fear of hospital and medical things... from when I first experienced the symptoms, it was probably about six or seven months before I went to the doctors." **Belinda**

Significantly more people from minority ethnic groups vs white reported difficulty in:



Getting an appointment (including due to long wait times and few slots being available)



Making time for the appointment due to work



These factors could be leading to **unequal diagnosis times** and **ultimately worse outcomes**





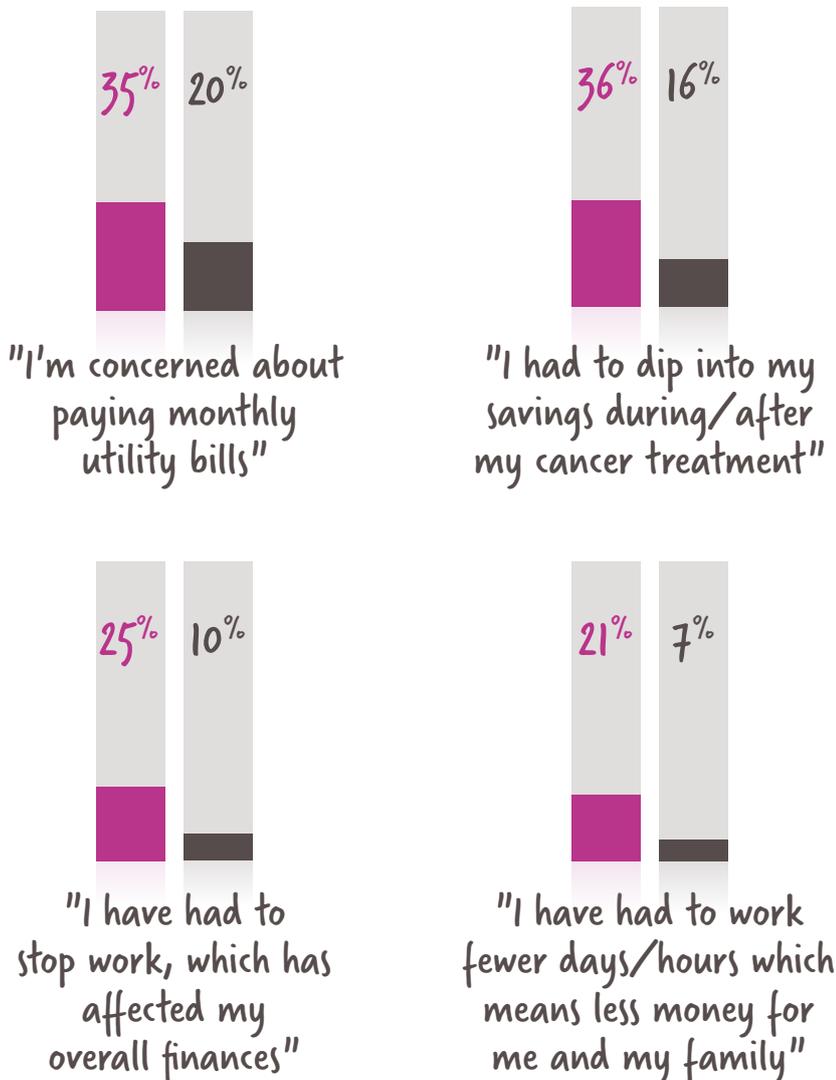
LIFE AFTER DIAGNOSIS

HOW are inequalities impacting people's experience of cancer?

Cancer is associated with wide-ranging concerns for people, including...

Financial and employment concerns

Proportion of people who felt the statement applied to them



Minority Ethnic   White

|| When I got diagnosed with cancer, I wasn't able to work for a long time because I was in and out of hospital. It was really tough. I didn't have a job, so I had to sign on and it was a huge drop in income for me. I got to a point where I went into debt.

I had so many people take advantage of my finances because for a long time, I wasn't in a position to make any financial decisions. I ended up working with some debt charities who helped me work my way out of debt. Cancer hits the finances, not only of the person going through it but also their loved ones. **||**

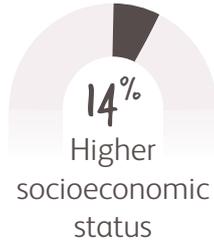
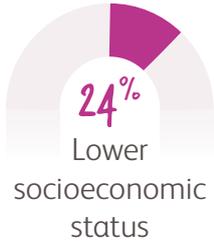
Precious



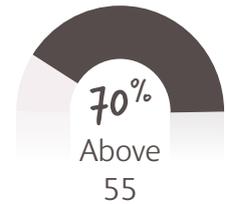
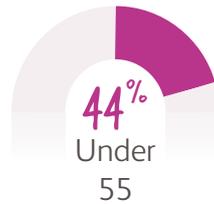


The **negative financial impact** of cancer is felt most strongly by minority ethnic groups, but also by people from lower socioeconomic status and under 55s.

"I had to dip into my savings during/after my cancer treatment"



"Cancer didn't impact my financial situation"



|| Once I had the diagnosis and I knew what was ahead, I had to give up work. I couldn't continue with the job mentally; I couldn't cope with it and worrying about the diagnosis. So financially, yeah, it did have an impact on me. || **Belinda**

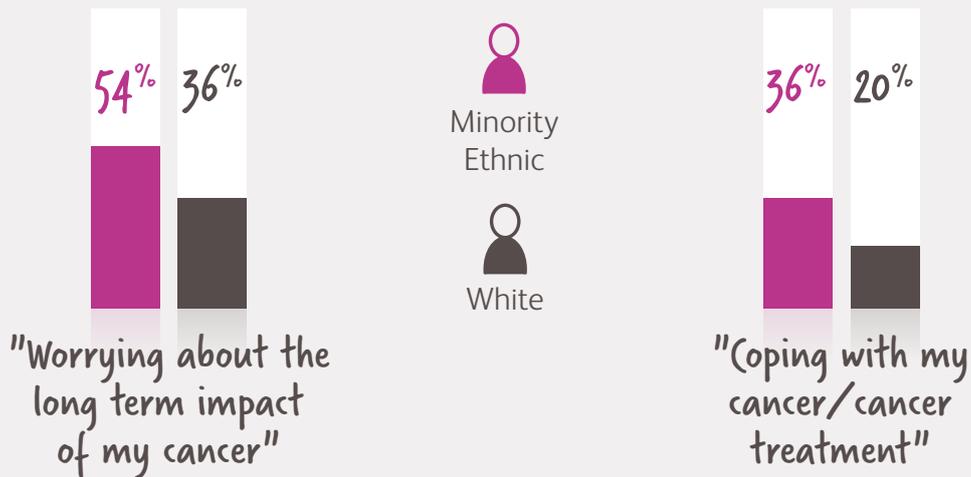
|| We were struggling financially, pretty much selling everything that we had that was of any value to keep a roof over our heads. I hadn't been working for a few years and couldn't claim benefits because of my immigration status. It was really, really tough. || **Simeon**





Concern from cancer is greatest in people from minority ethnic groups

Proportion of people who said they were MOST concerned with:



Impact on social and family life

Proportion of people who said they were MOST concerned with:

"Looking after my family"



"Maintaining a good social life"



|| Because I had some savings, I wasn't entitled to get any other benefits and I didn't really want to spend all my savings on my day-to-day life. By the time I paid my council tax, electric, and my car insurance I had virtually nothing left. ||

Anonymous respondent



WHO is being affected by inequalities in cancer?

People with a low awareness of cancer and their personal risk...

Meet Belinda...

My mother and her mother and her mother – so it's going back quite a few generations – they all died with bowel cancer. But I didn't consider I was high risk. I mean, they used to send me those test kits in the post and I never did them. I didn't really give it a lot of thought to be honest it was just something that was far away in the future.

That time I was living with my partner so he was quite supportive, but I don't think he really understood the seriousness of the illness that I had. I don't think I did. I don't think anyone really did.

From when I first experienced the symptoms, it was probably about six or seven months before I went to the doctors. It was just this one episode of being sick, and then probably a few days later, I was sick again and this continued for a long time until I was unable to eat very much at all... I don't know what I thought and why I didn't go to the doctors.





WHO is being affected by inequalities in cancer?

People from cultures where cancer is looked at as shameful...



Meet Precious...

I come from a community that doesn't talk about cancer. You hear people say, you know, cancer's a curse, it's something that happens to people who haven't lived well. So that's the sort of community I come from. There's a lot of shame around people having cancer and the whole concept of it. So, people don't talk about it and they do not get the help they should get, simply because they just want to hide away from the shame...

But if nobody is talking about cancer, people can't relate to anybody. The more we talk about it, the more we can get other people feeling safe enough to get the help that they need.

There's a whole population of Black and Asian people who have big cultural things behind them who need cancer demystified. And that's something I'm working on.





WHO is being affected by inequalities in cancer?

People who are below the typical age considered to be at risk of cancer...

Meet Alice...

I never needed a doctor very much. I had a reasonable diet, I exercised, I didn't think it was going to be anything serious when my symptoms first appeared. And with bowel cancer, you wouldn't think about it as anything more than just the changes that happen in your life. Because the first few changes are, you know, changes in your bowel habits.

You are not too young to have cancer. Please don't forget that. Please ask for the test. Please ask to be screened. Make sure you go for it.

I wasn't in the right age range to be diagnosed with cancer. It took three months from first seeing the GP before I received my cancer diagnosis. At that point, I ended up in hospital as a medical emergency and then waited nine days before I could have surgery. A week later I was told I had aggressive and incurable cancer.





WHO is being affected by inequalities in cancer?

People from minority ethnic backgrounds...



Meet Simeon...

Before I was diagnosed, I had no clue of my risk of cancer. But not long after my diagnosis, I started talking to family members and over the last five years, I've discovered that in three generations of my family, 56 males, including my three brothers, have had prostate cancer... but nobody talked about it.

By sharing experiences and raising awareness of some of the barriers that exist, it is possible to bring about change...

Black men are twice as likely as white men to get prostate cancer.¹ We get it younger,² so tend to be a working age and struggle to attend appointments, hold down a job and generate an income.

My involvement in the patient voice was because of my personal experience in accessing treatment and some of the barriers that I had to overcome. Some of the barriers might be quite small. For example, parking became a real problem because our local hospital charged.

1. Prostate Cancer UK. Black men and prostate cancer. Available at: https://prostatecanceruk.org/prostate-information-and-support/risk-and-symptoms/black-men-and-prostate-cancer?gad_source=1&gclid=EAIaIQobChMIk7DlmJqXhQMv4JJQBh-1jbQm9EAAAYASAAEgJFifD_BwE&gclidsrc=aw.ds. Last accessed: April 2024. 2. Medical News Today. What is the most common age for prostate cancer? Available at: <https://www.medicalnewstoday.com/articles/age-range-for-prostate-cancer>. Last accessed: April 2024.



WE NEED TO ACT Now To bring about change

There is no blanket solution to health inequalities, but awareness of different values and behaviours is a crucial step towards improvement.



Look beyond the default

Work to improve awareness of different values and cultures



Promote engagement with individuals

Understand the diversity within these groups. There is no single approach that will support all. However, encouraging targeted engagement with individuals and their needs, without judgment, will go a long way



Tackle access from both angles

The best time is before diagnosis, when people need to push through a series of barriers. Real change will come from working with populations, through tailored education and engagement

Join the conversation

Based on insights from the research, Bristol Myers Squibb is forming a *Cancer Equals* coalition to identify tangible solutions to reducing cancer inequalities in the UK. If you want to be kept up to date or to get involved, please contact us on: cancerequals@bms.com



|| *Let your voice be the catalyst for change and join us in the dialogue to make cancer care equal for all. ||*

Jagtar Dhanda, Director of Patient Advocacy and Government Affairs, Bristol Myers Squibb



|| *Together, we can turn the tide against cancer inequality; your participation in this conversation is a vital step toward a more equitable future. ||*

Ceinwen Giles, Shine Cancer Support

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