The unequal burden of multiple myeloma



Shining a light on ethnic disparities in blood cancer

Multiple myeloma, a rare blood cancer, is twice as common in Black ethnic groups than White or Asian.¹

People from Black Caribbean and African backgrounds are affected at twice the rate¹ and Black men have the highest incidence of any group.²

In the UK, whilst Black populations make up the second largest minority ethnic group, they:³



Have 2x the mortality rate for multiple myeloma



Develop the disease on average

4 years earlier

Currently, there is a limited understanding of the true impact of multiple myeloma in Black populations in the UK, though these disparities are believed to be caused by a range of factors including genetic and socio-economic.³

Much of our understanding comes from studies in the United States, and the limited data available which outlines the state of play in the UK is often outdated.

This highlights a need to conduct more UK-based research to truly understand the racial disparities and the needs of specific ethnic groups.





To begin to rectify this, Sanofi has collected data through a survey of 1,009 people from Black ethnic groups in the UK to understand disease awareness in an at-risk population. Respondents were predominantly from England and 38% were from London. This research expands our understanding of how knowledgeable at-risk populations in the UK are about the condition.

Sanofi Data on File, 2021 (REF-44600)

This infographic seeks to highlight the gaps in awareness and raise the profile of ethnicity as a risk factor for multiple myeloma. It aims to improve awareness amongst parliamentarians and policymakers to recognise that disparities in experiences and outcomes for rare cancers exist, and to encourage commitments to improving education as a way of closing equality gaps.

Key findings



77% of people surveyed had not heard of multiple myeloma.

Sanofi Data on File, 2021 (REF-44600



88% of respondents were unaware that ethnicity is a risk factor for the disease.

Sanofi Data on File, 2021 (REF-44600)

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What is multiple myeloma?

Myeloma is a cancer of the bone marrow, the spongy tissue at the centre of bones which produce the body's blood cells. It is often called multiple myeloma because the cancer can affect several different areas of the body, including the spine, skull, pelvis and ribs. There are around **6,000 new cases** of multiple myeloma in the UK each year. Multiple myeloma accounts for **15% of all blood cancers and 2% of all cancers**, and in the UK today, around **24,000** people live with the condition. Almost 30% of patients survive myeloma for 10 years or more in England however, there is currently no cure and survival is dependent upon many factors, including how early the condition is diagnosed.

Whilst prevalence in Black populations is higher than in White populations, awareness and understanding is low.

Members of the Black population, in particular men, have a higher chance of developing multiple myeloma in their lifetime and are more likely to present to their healthcare professional at later stages of the disease. Research has shown that multiple myeloma is twice as common in people with African heritage and disease onset occurs, on average, four years younger than in their Caucasian counterparts.⁷



One explanation for this slight increased inherited risk of disease is presence of specific genetic abnormalities linked to myeloma.⁷



Our survey highlighted that 77% of the surveyed population had **not heard of multiple myeloma**.

Sanofi Data on File, 2021 (REF-44600)

Of those who had heard of the condition:



Sanofi Data on File, 2021 (REF-44600)



Despite having the greatest risk of developing multiple myeloma, due to ethnicity,age and gender, Black men over 60 are the least knowledgeable out of the surveyed population about what multiple myeloma is and what the associated risk factors are.



Knowledge and understanding of the condition are paramount as patients who are already displaying symptoms need to start their treatment pathway quickly. Therefore, improving awareness of what is symptomatic of the condition, particularly in high-risk populations, is essential.

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The symptoms of myeloma are relatively generic which can make it difficult for a patient to recognise they need to see a healthcare professional, especially if they have not heard of the condition before. These symptoms often include:9



Bone pain (usually a dull ache).



Kidney problems (shown through weight loss and tiredness).



Unusual bleeding (for example frequent nose bleeds and bruising).



Weak bones (making them more likely to fracture).



Anemia (causing tiredness).



Weakness and shortness of breath, and repeat infections.



Multiple myeloma often causes no symptoms until it reaches an advanced stage of the disease so it can be difficult to diagnose early.8



Those who are at increased risk are not always likely to seek medical advice.



Treatment for myeloma is usually delayed until symptoms are occurring so getting patients who are presenting with symptoms onto a pathway and into the system quickly is essential.¹⁰



Fewer than 50% of surveyed Black adults would seek advice for fever, weakness and fatigue and the rate at which they would seek advice for these symptoms compared to others is significantly lower.



Reasons for this hesitation in seeing their GP include: not wanting to waste their doctor's time, having 'no reason' to seek medical attention, and feeling able to self-medicate.

The symptoms most likely to encourage Black adults to seek GP advice are:

Sanofi Data on File, 2021 (RFF-44600)



Brittle bone/frequent fractures



Bone pain



Fluid retention



After learning about the symptoms of multiple myeloma, Black adults are **significantly more likely** to visit their GP. The most popular sources to collect this information were internet search engines and GPs or pharmacists.

89%

of surveyed Black adults would visit their GP about at least one of the <u>multiple myeloma symptoms</u> earlier

if they understood the urgency of treating it.

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Calls to Action:

To tackle health inequalities, we are calling for the following:

Targeted awareness raising programmes to improve understanding in populations at greater risk of multiple myeloma

- At-risk populations must have better access to accurate information. For example, posters and leaflets should be available in trusted sources like community hubs and GP surgeries which outline symptoms and highlight the urgency of getting checked, as well as the role of ethnicity as a risk factor
- Education programmes should be proactive, reaching out to those most at risk and ensuring patients know when to ask for help and where they should go, enabling earlier diagnosis



Diagnosis and treatment protocols which reflect disparities in multiple myeloma, ensuring that clinicians understand risks and patients are moved through pathways more swiftly

- GPs in areas with high populations of at-risk patients should receive training to improve awareness and understanding
- Referral pathways should be streamlined to enable patients to access diagnosis and support at the earliest opportunity



Tangible and urgent commitments to reducing health inequalities to be made in Parliament and within the NHS. These should include commitments to:

- Address the lack of data, including on rare cancers in people of Black ethnicities in the UK
- Prioritise removing health inequalities for new Integrated Care Systems formalised through the Health and Care Bill



About Sanofi

Sanofi aim to provide hope to people with high unmet needs with specialty care and treatment for patient populations of under 200 to in excess of 100,000. Sanofi recognises the incredible burden that cancer has on patients and those who care for them. Its relentless pursuit to advance scientific discovery is matched only by its determination to bring solutions to patients. Sanofi is building on a rich legacy in oncology with a rejuvenated pipeline and a renewed commitment to bring novel treatment options to patients. Today, Sanofi has a portfolio of medicines across a variety of cancer, including skin, prostate, lung, colon, breast and blood.

For more information, or to discuss this briefing further, please contact Sanofi's Public Affairs and Advocacy Manager for Oncology Asha Kaur at asha.kaur@sanofi.com

1 NHS website. (2018) Multiple myeloma overview. Accessible at www.nhs.uk.conditions/multiple-myeloma (Accessed March 2022) 2 Cancer Research UK. Myeloma statistics. (Accessed March 2022) 3 The Basil Skyers Myeloma Foundation, Listen Up! Multiple Myeloma in Black Communities: An Unequal Risk Burden (2015), (Accessed March 2022) 4 Cancer Research UK. Myeloma statistics. (Accessed March 2022) 5 Myeloma UK. What is myeloma? (Accessed March 2022) 6 Cancer Research UK, Cancer Statistics, Myeloma, Survival. (Accessed March 2022) 7 Myeloma UK. What is myeloma? (Accessed March 2022) 6 Cancer Research UK, Cancer Statistics, Myeloma, Survival. (Accessed March 2022) 7 Myeloma UK. What is myeloma? (Accessed March 2022) 7 Myeloma UK. What is myeloma (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Survival. (Accessed March 2022) 8 Cancer Research UK. Myeloma, Surv

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