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Cancer Voices

Listening, Sharing & Acting: Addressing Health Inequalities in BAME Communities 4th December 2025

Summary Notes

Introduction

The Sunderland Bangladesh International Centre brings one of the strongest Black and Asian evidence bases in the Northeast, reaching **1,013 BAME residents** across cancer, end-of-life care, GP access, and community listening events. This depth of lived-experience insight underpinned the December convening, which brought together community leaders, GPs, hospital and trust representatives, academics, voluntary sector organisations, and public sector partners.

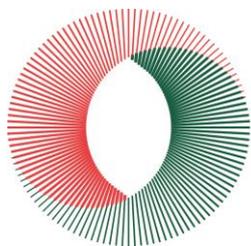
The following summary reflects:

Core Takeaways From The Day

- It's not Rocket science
- It does not have to be expensive; solutions can be low-cost!
- Need for culturally appropriate care.
- Listening and collaborating with BAME communities through participation and co-production is essential for adopting preventative approaches that focus on social determinants of health and the social model of health.
- Structural racism, as reflected in health inequalities, exists and has persisted for decades. We need to "turn the telescope around", prioritising Black and Muslim lived experiences at the beginning of diagnosis, rather than merely as a box to tick in policy.
- Increased and enhanced Black led capacity building for staff, professionals at all levels, and communities, with a particular focus on equality, inequality, and participation.
- Recognise the value of BAME community-led approaches and resource them effectively, ensuring consistency and accessibility to develop impactful, sustainable projects.

SBIC BAME Evidence-based

- SBIC BAME Macmillan Cancer report 2024 (724 Participants)
- SBIC End of life report 2024(78 BAME participants)
- Community Listening Event (27 November 2025 SBIC) 104 Participants
- GP Surgery Access Survey: Insights into Patient Experience SBIC (November 2025) 67 responses
- 4th December SBIC Health Day, 40 participants from health and care organisations
- Total number of SBIC BAME respondents: **1,013**



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Presentations

- 1) Professor Floor Christie-Jong, University of Sunderland School of Medicine: ICAM Study – Screening study 16 workshops, **261** Muslim women (2024)
- 2) Dr Sheikh Mateen Ellahi, GP Partner, Elm Tree Medical Centre. Stockton
- 3) Dr Zeb Sattar, Assistant Professor in Health Policy, Northumbria University
- 4) Dr Saeed Ahmed – South Tyneside & Sunderland NHS Foundation Trust

Summary Observations from the day

Intersectionality

Evidence at the global, regional, and local levels consistently shows a social gradient in health, with people in lower socioeconomic groups experiencing poorer health outcomes. Determinants such as housing, education, racism, and poverty heighten health risks, influenced by both systemic and individual factors. Health outcomes are influenced throughout the life course, from birth to old age, by policies and various social, cultural, environmental, and political conditions. Inequalities tied to gender, race, disability, and migration status are strongly associated with economic disadvantage, shaping how wealth and poverty are distributed in England. Intersectionality reveals these forms of injustice do not occur independently but are interlinked, resulting in complex patterns of privilege and oppression.

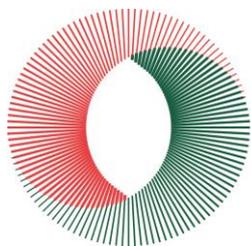
As stated, health is strongly influenced by social and economic factors, the physical environment, and the extent to which our health services can respond. These determinants have a much larger effect on health outcomes than individual choices like alcohol use, diet, smoking, or similar behaviours. Moreover, the environments and communities surrounding us play a significant role in shaping our personal health behaviours.

SBICs' lived experience of social and economic inequality, racism, and Islamophobia enables them to engage with and support hard-to-reach racially minoritised communities, which mainstream services often struggle to access. Language, cultural affinity, cross-generational membership, and trust rooted in shared experiences of forced exile, discrimination, and inequality facilitate the design and delivery of co-produced health and care services.

There is a well-established case for involving communities and people with lived experience in health and care policy, service design and delivery. Engaging with people with lived experience on society's margins should always be a priority. Organisations must consider adopting an intersectional approach and fostering an inclusive environment where services genuinely connect with BAME marginalised groups whose voices are often overlooked

Population Changes

There is a need to recognise rapidly changing population patterns, especially in Tyne & Wear, within the Health, Care, and public sector services. For example, census data from 1981 to 2021 show a consistent decline in the City of Sunderland's population, from 294,102 to 274,200, a



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6.7% decrease of 19,902 people. Meanwhile, the racially minoritised population increased by 266% between 2001 and 2021. Analysis of Census 2021, mid-term census data from 2024-25, HESA 2025, and the Migration Observatory indicates that the racially minoritised population in Sunderland is approximately 41,677. Such population shifts are also reflected within the Tyne and Wear sub-region.

The Tyne & Wear population has risen by 4.16% from the 2021 Census to the 2024 mid-year estimate, reflecting an annual growth rate of 1.37%. Using this projection, the population of Tyne & Wear could reach 1,245,000 by mid-2028 (around 100,000 more in 7 years). Assuming 20% of this increase results from births, the remaining 80%, or 800,000, would be due to migration, whether domestic or international.

Culturally Appropriate Care.

BAME respondents highlighted the shortage of culturally suitable and faith-informed health and care services. There is a need for a thorough understanding of culturally appropriate and faith-based health and care services, informed by BAME lived experiences, particularly in relation to ageing, long-term care, end-of-life care, gender-specific care, food, drink, clothing, and faith within health and care environments.

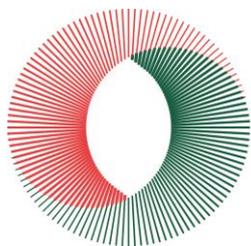
There is a need for Black/Muslim-led, lived-experience, culturally appropriate training within the NHS, care, and medical support services. Target and identify trusted Black, South Asian, and Muslim community partners to promote culturally appropriate health and care, identify barriers, and explore solutions to health inequalities, such as access to services. The floor emphasised the importance of "white allies who actively challenge inequality and support inclusive practice."

Methods of BAME Engagement

BAME evidence to date, including speakers, emphasised that participatory approaches, such as Participatory Action Research, Asset-Based or Strengths-Based methods that involve and respecting BAME communities, are crucial for addressing BAME health inequalities and building trust through co-design and co-ownership with BAME users, patients, communities, and stakeholders as active partners and experts in their own lives in the design, implementation, and evaluation of health services.

This results in practical, relevant, and empowering health solutions. Moving away from hierarchical models, the focus is on collaboration, trust, shared decision-making, and the use of local knowledge to improve outcomes. Visual, accessible tools further encourage diverse participation. Rather than focusing on problems, these approaches assess situations realistically and identify opportunities to leverage the strengths of BAME communities. They work with communities, organisations, and groups to celebrate strengths, shifting the focus from 'what is wrong with us' to 'what is right with us.'

BAME Community Led Health Development Approach



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A community-led health approach supports BAME communities experiencing disadvantage and poor health outcomes by A) identifying and defining what matters most to them about their health, B) identifying the factors that affect well-being, and C) taking the lead in recognising and implementing solutions. By focusing support on people and communities experiencing health inequalities, disadvantage, and marginalisation, this approach enhances the health and well-being of not only those directly involved but also the wider community.

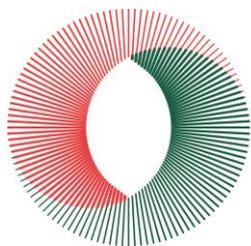
Community-led health also promotes preventive strategies that build and sustain good health, helping prevent illness before it occurs. Characteristics typical of BAME community-led health approaches align with the core values of these methods, supporting personal and collective empowerment, equity, social justice, and the right to good health for all.

- Operate in BAME communities affected by poverty and deprivation.
- Focus on priorities identified by the local community.
- Employ participatory approaches that directly engage BAME patients and residents. Deliver services to reduce health inequalities, guided by the social model of health.
- Include BAME community members in co-production and governance, and work with voluntary, statutory, and business-sector partners as needed.
- Share resources efficiently and provide a unified voice representing community interests. Black-led Community Health Activators within communities identify barriers, enhance access to services, boost health literacy, and strengthen links between BAME communities and statutory systems.

Evidence: Data Capture

There is a need for a co-designed Participatory Action Research approach that combines traditional quantitative and qualitative methods with collaboratively developed pilots to gather bottom-up, lived-experience insights that challenge conventional narratives and inform service design to address health inequities faced by BAME communities. This is not just about collecting stories; it's about recognising lived experience as expertise and using it to rewrite the evidence base, influence commissioning, and create a more equitable, responsive health system. It should include a BAME-majority community advisory panel and academic partners to explore an ethnicity-disaggregated neighbourhood access audit (GP registrations, screening uptake, non-elective admissions, missed appointments by ward/PCN, data overlays linking health access to housing, employment, poverty, debt, Track engagement, participation, and barriers).

Practice & academic learning: Formal links with the University of Sunderland Medical School, Northumbria University, the Institute for Economic and Social Inclusion, UCL, and the Insights North East consortium. There is a need to combine Black-led research methods, such as narrative inquiry and participatory action research, with academic rigour. Policy engagement: establish connections with Primary Care Networks, public health teams, ICB, and NECA to offer pathways for pilot adoption. The need for regional and sub-regional scale-up, building a resilient



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learning network, sustaining BAME community-led approaches and strengthening representation in health professions.

Appointment Access

Based on the evidence presented, access to GP/Health/Care is reported to be poor, with 80% BAME respondents stating difficulty securing appointments and long waiting times, compounded by language, communication, and translation issues. Translation can add weeks to the appointment. Respondents indicated that their initial contact with the practice is via phone (60%), followed by eConsult (35%) and online (5%). BAME respondents reported privacy issues with eConsult, too many questions, difficulty expressing integrated/complex symptoms, and a drawn-out process. There is a need for face-to-face, telephone, and open dialogue.

It is important to communicate directly with BAME communities to identify access barriers, while enhancing translation services, face-to-face appointments, and culturally sensitive triage pathways. Additionally, consider exploring neighbourhood care models and community outreach clinics.

Screening

Screening involves early detection, lifestyle modifications, or surveillance to reduce disease risk or identify it early and involves selecting individuals for further testing to determine whether the disease is present. There is a need to explore PocDoc testing and similar community-based screening tools. The presentation by Professor Floor Christie-Jong and the evidence to date highlight that active community involvement in participatory health research is essential to addressing health disparities. Whilst faith-based strategies, a type of asset-based approach, can be particularly effective in ensuring cultural relevance and enhancing health outcomes.

Socio-economic and ethnic inequities in cancer and its screening persist, and uptake of cancer screening is lower in deprived areas and compounded within BAME/Muslim communities. According to the 2021 census, there were 3.9 million Muslims in the UK, and 40% live in the most deprived areas based on the Index of Multiple Deprivation. Evidence to date highlights that 'One size fits all' public health Interventions do not work for everyone. Their programme intervention is a combination of medical and Islamic perspectives, resulting in a significant increase in the intention to engage in screening, which increased significantly from pre-intervention to 12-month follow-up for:

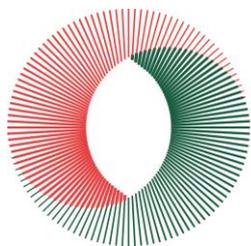
- Breast (55% to 92%)
- Cervical (43% to 83%)
- Bowel (35% to 85%,)

Digital Access to Primary Care

National and regional reports such as Good Things Foundation's Our Digital Nation 2025, Lloyd's 2024 Index, and Ofcom's "Exploring Digital Disadvantage" 2025 highlight the ongoing digital divide in the UK. For example, more than half of the workforce cannot perform 20 essential digital tasks; 8.5 million people lack digital skills; 3.7 million families live below digital standards; and

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21 million adults are unable to complete basic digital work tasks. BAME ethnic groups and those with Limited English Proficiency face significant digital disadvantages, including difficulties navigating online systems, dependence on family for translation, and exclusion from healthcare and employment opportunities.

Furthermore, some patients either lack smartphones or are uncomfortable using digital platforms. Language barriers also limit access to the NHS app and digital triage systems, which can be complicated and involve multiple steps before reaching a GP. Older adults often depend on family members for help with these apps. Improving access to digital services requires education, usability improvements, and targeted support, particularly for older adults and non-English speakers in BAME communities.

Working with BAME-led community partners to provide digital training and guidance on using the NHS app and understanding its features is essential. Create educational resources and support for the use of digital platforms. Examine a simplified triage process for older or less technologically proficient users. However, technology alone cannot solve access issues; support, education, and inclusion remain vital. There is a need to increase BAME-led proofing of digital tools/AI Apps. A BAME-led “proofing Hub” to test and roll out NHS/GP/Care AI App’s and platforms, creating a digital Hub with links to workers providing translation and support.

Call For Action

Identify the Steering Group and lead participants to take forward two to three action points within the next 14 days, focusing on the following areas identified during the day.

- 1) Evidence highlighted the need for more culturally appropriate care within health and care environments. Objective: to build upon and expand SBIC’s existing Black-led culturally appropriate training module for mainstream NHS staff and GP practices. Evaluate the training model regarding its impact on patients and staff.
- 2) Evidence highlights the barriers BAME patient users face when accessing health and care appointments, including digitalisation, eConsult, translation, and appointment scheduling. A small working group, including GP alliance, is exploring good practice and making reference to Dr Sheikh Mateen Ellahi
- 3) Exploration, design and implementation of BAME / faith-based health/care screening pilots and associated impact analysis, building upon good practice of Dr Floor Christie-de Jong

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