UNIVERSITY OF LEICESTER

The Centre for Ethnic Health Research

THE REPRESENT STUDY:

HEALTH AND SOCIAL CARE EXPERIENCES AND RESEARCH PRIORITIES AMONG ETHNIC MINORITY COMMUNITIES

INTRODUCTION:

This report presents findings from the REPRESENT study, which explored the experiences of people from ethnic minority communities and other under-represented groups in the East Midlands carried out between May and September 2022. The study examined how people access health and social care services, the challenges they face, and their views on health research.

People from ethnic minority communities and under-represented groups often experience poorer health outcomes and face barriers when accessing services. They are also underrepresented in research, which means services and research are not always designed around their needs and experiences.

The study highlights the importance of listening to communities and understanding what needs to change to make healthcare and research more inclusive, culturally accessible, fairer, and responsive.

HOW WAS THE STUDY CARRIED OUT?

The study used a mixed-method approach to gather people's experiences and views.

This included:

- **Nine focus groups**
- **Seven one-to-one interviews**
- **A national survey**
- **Partnership working with community organisations**

Community members through the involvement of the study Advisory Group and co-production workshops also helped shape the study design and questions to ensure they were clear, respectful, and culturally appropriate.

WHO TOOK PART?

Fifty-two people from ethnic minority communities and under-represented groups took part in focus groups and interviews. The study also included a national survey involving 982 participants, enabling broad engagement with diverse communities and strengthening the reach of the research. The dissemination and uptake of the survey were supported through partnerships with 10 community organisations.

Participants came from a range of communities, including:

- African Caribbean
- South Asian
- Somali
- Eastern European
- Gypsy, Roma and Traveller communities
- Refugee and Asylum Seeker communities
- LGBTQIA+ communities

Healthcare staff, carers, and researchers also shared their perspectives.

Participants represented different characteristics, including a range of ages, backgrounds, and lived experiences. Many people were reached through trusted community groups and local networks, helping to ensure a wide range of voices were included.

KEY FINDINGS

The study identified three main themes and explored participants' understanding of research, barriers to participation, and factors influencing their motivation to engage in research.

A word cloud was created of the most common 100 words participants used. These words illustrated participants' reflections on the importance of social and health care in the community through health research for people, information and experiences.

Theme 1: Health and Social Care Priorities

Participants identified several important health and social care areas. .Primary health priorities included:

- Cancer
- Hypertension and heart conditions
- Diabetes
- Mental health
- Dementia
- Chronic pain and musculoskeletal conditions
- Obesity
- Sickle cell

Maternal health, child development, autism, and dental health were also identified as important areas needing more support and research.

Participants highlighted several social care priorities, including:

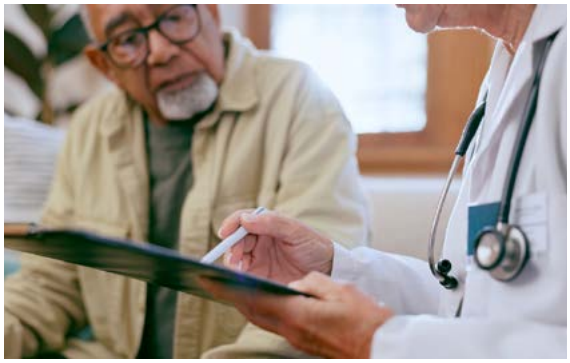
- Access to care and support
- Support for carers
- Language support
- Help understanding and navigating services
- Care that respects different cultures and experiences

Many participants emphasised the importance of early intervention, prevention, and regular health checks to reduce more serious health problems later.

Research priorities closely reflected these topics. . Participants wanted research that focused on long-term conditions, prevention, health promotion, improving access to services, and understanding the impact of discrimination and cultural barriers on health outcomes.

The study also found that priorities differed between communities depending on people's backgrounds, age, gender, experiences, and health needs. This highlights that a "one-size-fits-all" approach is unlikely to meet the needs of all communities and under-represented groups.

Theme 2: Access to Health and Social Care



Participants described a range of challenges when trying to access services.

Language difficulties were among the most significant challenges, particularly for older adults and recent migrants. One participant explained that "language barrier in health can be a big problem… we did not have the language skills to be able to understand the full story" (pg.7). These barriers contributed to delayed help seeking, communication difficulties and, in some cases, avoidable complications.

Many participants also reported:

- Difficulty getting GP appointments
- Short consultation times
- Long waiting times
- Limited culturally appropriate information
- Poor communication and lack of cultural understanding
- Experiences of discrimination, stigma, or mistrust

Some participants described avoiding interactions with healthcare because of fear, previous negative experiences, or concerns about being judged.

Despite these challenges, participants also identified approaches that helped improve access. These included:

- Healthcare staff who spoke their language
- Community-based health sessions
- Clear and culturally sensitive communication
- Trusted community organisations and faith groups
- Private one-to-one conversations about sensitive topics

Community pharmacies were also viewed positively because they were accessible, trusted, and easier to approach than some formal healthcare services.

Theme 3: Trusted Sources of Information

Community organisations were seen as very important sources of support. These groups provide trusted, community based spaces where people can ask questions, share experiences, and receive guidance. The study notes that "the most influential information sources were local community organisations and word of mouth" (pg.1). Pharmacies, faith networks and community champions were also seen as reliable sources of information, often more accessible than formal healthcare services.

Although many participants used online sources such as Google, they found the information confusing, contradictory or a source of anxiety. Some groups, particularly those with limited digital access or literacy, were excluded from online information entirely.

Research understanding, barriers and motivators

Participants' understanding of research varied widely. Some had limited awareness of what research involves or how it benefits their communities. Others associated research with risk, experimentation, perceptions of being used as "guinea pigs" or lack of relevance. Barriers to participation included distrust of institutions, language challenges, time constraints and the perception that research does not address the needs of ethnic minority communities and under-represented groups.

However, participants expressed openness to take part in research when it was clearly relevant, culturally appropriate and communicated in a respectful and accessible way. The study highlights that improving research interest requires "understanding individual community needs, community sensitivity, research relevance and cultural appropriateness" (pg.1).

What Motivates People to Participate in Research?

Trust was one of the most important factors influencing whether people chose to participate in research.

Participants were more likely to engage when:

- Research felt relevant to their community
- Communication was clear and culturally sensitive
- Researchers treated people with dignity and respect
- Community organisations were involved
- Flexible ways of participating were available

Practical considerations were also important. Participants valued:

- Convenient locations
- Flexible timings
- Incentives such as travel reimbursement or vouchers
- Health checks or referrals where appropriate

Participants also wanted researchers to share findings back with communities and demonstrate how the research could lead to positive change.

Importantly, motivation was not only about incentives. People wanted to feel heard, respected, and confident that their involvement would benefit their communities.

RECOMMENDATIONS

Participants made several recommendations for improving health services and research.

Improving Services

Participants said services should:

- Communicate clearly and accessibly
- Provide information in different languages and formats
- Improve cultural understanding of healthcare staff and reduce bias
- Reduce waiting times and improve appointment systems
- Increase support in community settings
- Focus more on prevention and early intervention

Improving Research

Participants also highlighted the importance of:

- Involving communities from the beginning of research
- Building long-term relationships and trust
- Designing research to ensure it reflects community needs, priorities, and lived experiences.
- Sharing findings back clearly and accessibly
- Ensuring research leads to meaningful change

The study highlights that effective engagement takes time and requires genuine partnership working with communities.

CONCLUSION

The REPRESENT study highlights the challenges many ethnic minorities communities and under-represented groups face when accessing health and social care services. These challenges include language barriers, poor access to services, limited cultural understanding, discrimination, and mistrust.

At the same time, the study shows that communities are open to engage with healthcare services and research when they feel respected, included, and understood.

Community organisations, faith and local networks play a vital role in building trust and improving access to information and support.

Improving health and care systems will require stronger partnerships with communities, better communication, culturally responsive services, and meaningful involvement in research.

By listening to communities and acting on their experiences, healthcare services and research can become more inclusive, effective, and equitable for everyone.

Further information about the study can be found on

Health and social care experience and research perception of different ethnic minority populations in the East Midlands, United Kingdom (REPRESENT study)

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