



THE REPRESENT STUDY

ABOUT:

What is the REPRESENT study?

A study exploring:

- Health & social care priorities
- Barriers to accessing care
- What encourages research participation



Why was this needed?

People from ethnic minority backgrounds often:

- Experience poorer health outcomes
- Are underrepresented in research
- Feel unheard or misunderstood
- May mistrust research due to past experiences



How was the study conducted?

- **9** focus groups
- **7** interviews
- National survey (**982** participants)
- **10** community organisations involved



Who took part?

Communities included:

- | | | |
|---------------------|-------------------------------|-----------------------------|
| • African Caribbean | • LGBTQIA+ | • Somali |
| • South Asian | • Gypsy, Roma, and Travellers | • Refugees & Asylum Seekers |
| • Eastern European | | |



KEY FINDINGS:

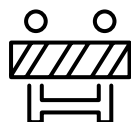
ACCESS TO CARE

Barriers people face

- ✗ Long waiting times
- ✗ Discrimination & stereotyping
- ✗ Language barriers
- ✗ Poor communication
- ✗ Fear of stigma

Access depends on:

- ✗ Language skills
- ✗ Health literacy
- ✗ Urgency of need



TRUSTED & PREFERRED SUPPORT:

People trust:

- ✓ Community pharmacists
- ✓ Staff from similar backgrounds
- ✓ Community organisations

These improve:

- ✓ Communication
- ✓ Confidence
- ✓ Access



VIEWS ON RESEARCH:

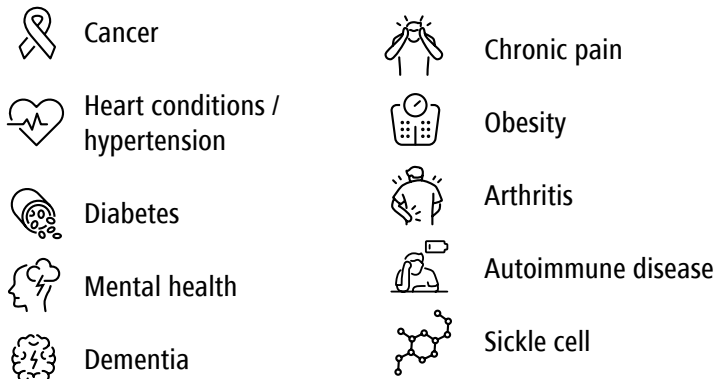
Mixed understanding, with key barriers:

- ✗ Lack of trust
- ✗ Privacy concerns
- ✗ Communication difficulties
- ✗ Limited awareness
- ✗ Lack of feedback



PRIORITIES IDENTIFIED:

HEALTH PRIORITIES



SOCIAL CARE PRIORITIES

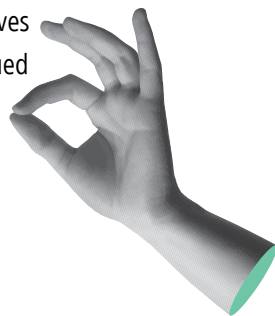
- Access to care
- Education
- Community support
- Substance misuse
- Domestic violence & discrimination



WHAT MOTIVATES PARTICIPATION IN RESEARCH?

People are more likely to take part when:

- ✓ Research is relevant to their lives
- ✓ Their lived experience are valued
- ✓ They feel respected
- ✓ Communities are involved from start to finish
- ✓ Incentives are offered
- ✓ Results are shared clearly
- ✓ Participation is flexible



KEY TAKEAWAYS

- ✓ No “one-size-fits-all” solution
- ✓ Different communities have different needs
- ✓ Priorities vary by age, culture, and experience
- ✓ Trust is built through consistent, visible community engagement
- ✓ Clear, accessible communication is as important as the research itself



WHAT NEEDS TO HAPPEN NEXT:

TO IMPROVE HEALTH & RESEARCH:

- ✓ Communicate clearly and honestly
- ✓ Build trust over time
- ✓ Respect culture and language
- ✓ Involve communities early
- ✓ Make research relevant to real life

When people are involved, health systems become more equitable and effective



Funded by
NIHR | National Institute for Health and Care Research

This project is funded by the NIHR Applied Research Collaboration East Midlands (ARC EM). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.