Kent Academic Repository

Khan, Nagina (2024) ***Improving diversity in research: Learning from the perspectives of minority communities in the UK.*** **. Mental Elf website.**

Downloaded from

https://kar.kent.ac.uk/111402/ The University of Kent's Academic Repository KAR

The version of record is available from

https://www.nationalelfservice.net/populations-and-settings/black-and-minority-ethnic/improving-diversi

This document version

Publisher pdf

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Mental Elf blog article

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in ***Title of Journal*** , Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

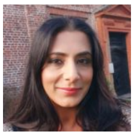
If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

NO BIAS. NO MISINFORMATION. NO SPIN.
JUST WHAT YOU NEED!

The Mental Elf

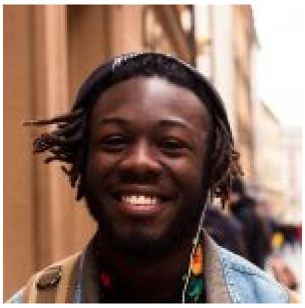
JUN
10
2024

Improving diversity in research: Learning from the perspectives of minority communities in the UK



Posted by
Nagina Khan>,
Nina Higson-Sweeney

No Responses »



Health and social care research is undertaken to inform and broaden our understanding of different topics and phenomena before we make decisions in practice (National Institute for Health Research, n.d.). Diversity is an important element to consider when conducting this kind of research, but seems to have posed something of a challenge for both qualitative and quantitative researchers in the social sciences.

Evidence suggests that research often fails to adequately represent the voices of ethnic minorities, despite recognition that these populations experience a greater burden of disease and poorer treatment outcomes (Smart et al., 2017). As research can lead to the development of treatment guidelines which influence clinical practice, **the absence of these voices means that treatments generated and utilised as not necessarily generalisable, applicable, or helpful for ethnic minority populations**. This works to amplify health inequalities.

It is therefore important to ensure that health and social care research includes participants from underrepresented groups. However, there are still **barriers to research participation among minority groups**, such as lack of understanding and lack of necessary resources to facilitate engagement (Brown et al., 2014). As such, it is important to develop a comprehensive understanding of research experiences, interests, and priorities among minority groups – which is what Ekezie and colleagues (2023) aimed to do.

As research plays a key role in the development of healthcare guidelines, it is important that a diverse range of voices are represented. If this doesn't happen, there is a risk that the treatments developed will not be generalisable or helpful.

Methods

The REPRESENT study is a programme of research designed to explore research priorities relating to health and social care among ethnic minority populations in the UK. The current article presents some of the project's qualitative findings, which were collected from minority communities, healthcare providers (HCPs), and researchers in the East Midlands between May and September 2022.

The REPRESENT study was supported by ethnic minority members of the Centre for Ethnic Health Research, alongside members from Patient and Public Involvement and Engagement (PPIE) groups. Members representing different categories within the Equality Act helped to review the topic guide to make sure it was appropriately relevant and sensitive. The research findings were also reviewed to ensure cultural accuracy.

Data was collected through focus groups and semi-structured interviews, and analysed using thematic analysis.

Results

A total of 52 individuals participated in either focus groups (*n* = 45) or one-to-one interviews (*n* = 7). Focus group participants came from a diverse range of minority backgrounds, including ethnicity (*n* = 34; African Caribbean, Eastern European, Gypsy Travellers, Somali, South Asian), but also sexuality (*n* = 4) and refugee/asylum seeker status (*n* = 7). This was because the authors' definition of 'ethnicity' was broad, and they wanted to include all protected characteristics under the Equality Act 2010. Interview participants included researchers, carers, nurses/midwives, and general practitioners (GPs).

Analysis generated three main themes:

Theme 1: Health information and healthcare seeking actions

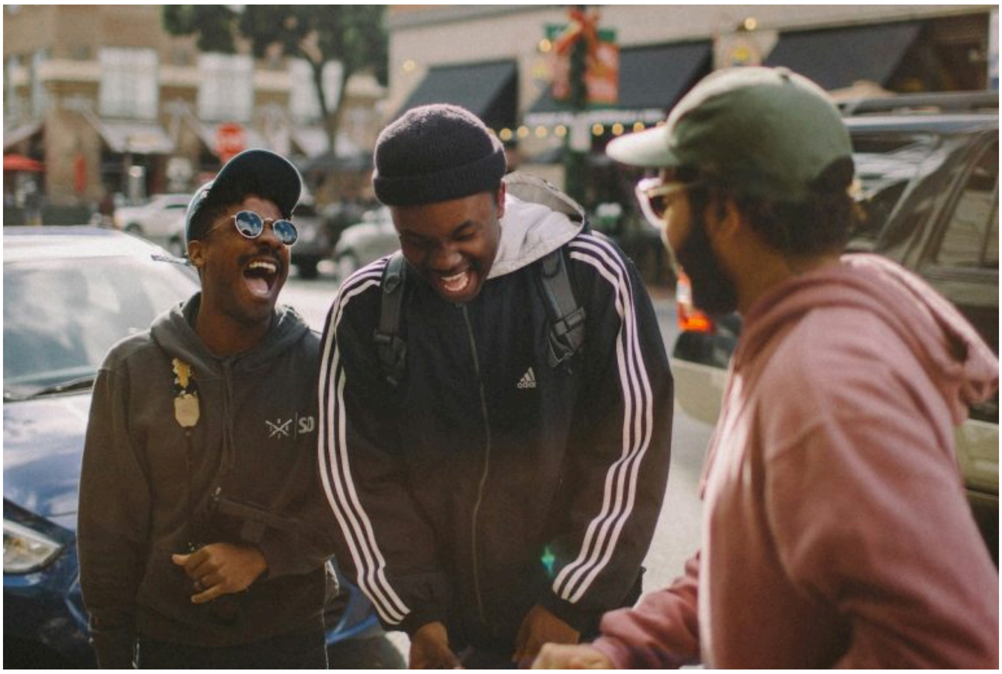
- Participants **often searched for healthcare information online**, using platforms like Google. However, the information was sometimes perceived as **confusing or unreliable**, and didn't always include what they were looking for. Further, not everyone had the **language skills or technology** to seek healthcare information online, which led to a delay in help-seeking.
- Community organisations were seen as a **good alternative** for seeking health information, particularly when events were organised that allowed members of the public to interact with HCPs.
- Insufficient time, lack of cultural understanding, difficulty in accessing GP appointments, and previous negative experiences were barriers for seeking information through official health channels.
- **Key recommendations included:**
    - Improving healthcare communication within communities;
    - Increasing access to bilingual HCPs and community champions;
    - Greater access to private, one-to-one support.

Theme 2: Medical, health and social care service experiences

- **Subtheme: Access to services**
    - **Poor access to services** was a considerable barrier, including short appointment times, lack of availability, and language barriers.
    - These barriers meant that some conditions **were not taken seriously**, like chronic pain, whereas other chronic conditions, like cancer or diabetes, **became more complicated due to delays**.
- **Subtheme: Discrimination**
    - Participants shared how they felt **judged, ignored, and dismissed by HCPs**, which led to poorer medical attention.
    - Taboos and poor awareness of mental health was also influenced by **racial or cultural discrimination**, which led to an avoidance of services.
- **Key recommendations included:**
    - Increasing early intervention among ethnic minorities communities.

Theme 3: Health research

- **Subtheme: Research understanding, barriers and motivators**
    - Across communities, there was a **low history of research participation**, although some did perceive research favourably due to past positive experiences.
    - **Incentives were seen as a way to increase motivation** to take part in research, but were not necessarily enough on their own to encourage participation.
    - Some participants were reluctant to take part in research due to **perceptions of being used as "guinea pigs"** and a **lack of direct benefit** to them or their communities.
    - **Key recommendations included:**
        - Ensuring that participants are told about research outcomes and the impact it will have on their community;
        - Increasing community confidence in health and social care services;
        - Involving and empowering communities with research.
- **Subtheme: Research recommendations**
    - The most popular areas of research interest were cancer, diabetes, high blood pressure, mental health, sickle cell disease, and health promotion.
    - Social care research priorities included early intervention, social isolation, substance misuse, and understanding community needs.
    - Training for HCPs, alongside linguistic support and referral services were also highlighted as core priorities.



Participants from minority groups highlighted a range of barriers to engaging with research, including the perception of no direct benefit to themselves or their communities.

Conclusions

The findings from Ekezie et al. (2023) paint a troubling picture that emphasises how **cultural discrimination and lack of understanding can lead to disengagement and underrepresentation of ethnic minority voices within health and social care services and research**. It also provides insight into how additional factors such as poor service provision, language barriers, and lack of cultural sensitivity can exacerbate illnesses, and further contribute to feelings of apprehension and distrust.

Ethnic minorities may be more likely to turn to their communities for healthcare advice rather than official healthcare providers. Increasing community confidence in health and social care services is vital for change.

Strengths and limitations

Strengths

- The study largely makes **appropriate use of qualitative methods** for data collection and analysis, which are clearly reported in the main paper. This **aids our confidence in the rigour and robustness of the study** and its findings.
- A main strength of this study lies in their **collaboration with PPIE contributors**. PPIE (patient and public involvement and engagement) in research is important because it helps researchers to better understand the perspectives of the groups they are studying and ensures that their research is appropriate and applicable. In turn, this has an influence on the knowledge generated by the research.

- Although the reporting of recommended research areas within the main paper is poor, **the authors have provided supplementary materials** which explain in detail the range of research areas the different groups wanted to see prioritised. This is really useful information that can be used by researchers and policymakers to understand the needs of these minority populations.

Limitations

- Whilst the researchers took steps to ensure that the focus groups were organised based on community and identity, **some may have found it difficult to be open and honest about such a personal topic** in front of others. There were opportunities for one-to-one interviews, **but it is not clear who these were made available to** in the main paper.
- The authors acknowledge that **the sample was limited to selected ethnic minority communities from the East Midlands**, which reduces the generalisability of the findings to the wider UK population and other countries.
- The authors briefly mention reflexivity, **but have not provided a reflexive statement** in the main paper or supplementary materials. This makes it difficult to understand the potential impact the research team had on their analysis, which reduces the transparency and confidence in the findings.
- In addition to the above, **some members of the research team had previously engaged with some of the participants in different projects**. Again, because there is no reflexivity, it is difficult to tell the impact and potential bias.
- Finally, it is not entirely clear why the paper first focuses on ethnic minority communities, but switches partway through to also include broader minoritised groups. While accessing and representing these voices is very important, it makes the paper difficult to follow.

There are several strengths to this study, including their use of Patient and Public Involvement and Engagement (PPIE); but the authors also fail to provide a reflexivity statement that reflects how their identities, experiences, values and beliefs may have influenced the research.

Implications for practice

Practice

- There is a clear need for culturally sensitive health and social care services, with HCPs who are **trained in understanding cultural concepts of distress**. This has been consistently identified as facilitating access and engagement with healthcare services among minority ethnic groups (Pilav et al., 2022).
- **Build relationships between services and communities** to improve trust and facilitate direct communication. This could involve speaking on community radio stations, or drop-ins at community centres.
- Ensure that patients have **adequate access to private one-to-one support**, both in community settings and within clinics.

Research

- When designing research that involves minoritised groups, consider the potential barriers they may experience in relation to engaging in research, **and proactively implement ways for overcoming these barriers** (e.g., explicitly outlining in the participant information sheet how you will ensure that participants are updated with the study results).
- **Engage communities at the outset** of any research project and find ways to **empower them in leading research activities**.
- Conduct research that is **focused on the topics that minority communities find most important**, and **include incentives** for research participation.

Policy and funding

- Minority communities may be reluctant to seek help for their health due to experienced barriers. This means that **more focus and funding should be directed towards early intervention** and ensuring that those that need help feel able to seek it.
- Provide funding to minoritised communities to **skill up leaders as community champions** who can provide early advice, support, and signposting to health and social care services.
- **Increase linguistic support** within health and social care services, particularly in areas where there are large populations of those who do not have English as their first

language.

- **Consider which services and HCPs minority communities already utilise** (e.g., pharmacists) and increase funding to support early intervention and signposting.

When designing research that involves minoritised groups, it is important to proactively implement methods for overcoming potential barriers to research engagement.

Statement of interests

None.

Links

Primary paper

Ekezie, W., Cassambai, S., Czyznikowska, B., Curtis, F., O'Mahoney, L. L., Willis, A., … & Farooqi, A. (2024). Health and social care experience and research perception of different ethnic minority populations in the East Midlands, United Kingdom (REPRESENT study). *Health Expectations*, *27*(1), e13944.

Other references

Bhopal, R. (2004). Glossary of terms relating to ethnicity and race: for reflection and debate. *Journal of Epidemiology and Community Health*, *58*(6), 441–445.

Brown, G., Marshall, M., Bower, P., Woodham, A., & Waheed, W. (2014). Barriers to recruiting ethnic minorities to mental health research: a systematic review. *International Journal of*

Methods in Psychiatric Research, *23*(1), 36-48.

National Institute for Health Research. (n.d.). *What is health and care research? – Be Part of Research*. Retrieved February 13, 2024, from https://bepartofresearch.nihr.ac.uk/about/What-is-health-and-care-research/

Pilav, S., De Backer, K., Easter, A., Silverio, S. A., Sundaresh, S., Roberts, S. & Howard, L. M. (2022). A qualitative study of minority ethnic women's experiences of access to and engagement with perinatal mental health care. *BMC Pregnancy and Childbirth*, *22*(1).

Smart, A., & Harrison, E. (2017). The under-representation of minority ethnic groups in UK medical research. *Ethnicity & Health*, *22*(1), 65-82.

Photo credits

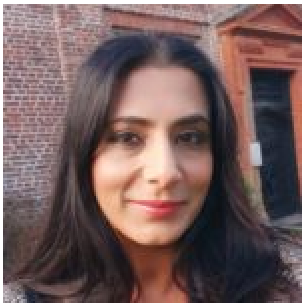
- Photo by Yingchou Han on Unsplash
- Photo by Greg Rosenke on Unsplash
- Photo by Jed Villejo on Unsplash
- Photo by Aarón Blanco Tejedor on Unsplash
- Photo by Vince Fleming on Unsplash
- Photo by Zachary Nelson on Unsplash

MARK AS READ

CREATE A PERSONAL ELF NOTE ABOUT THIS BLOG

Share this post:

Tagged with: access to services, asylum seekers, barriers, black and minority ethnic communities, diversity, focus groups, Health Expectations, health inequalities, healthcare professionals, inequalities, minority groups, patient and public engagement, patient and public involvement, qualitative study, racial inequalities, racism, refugees, refugees and asylum seekers, research, semi-structured interviews, sexual minorities, underrepresentation

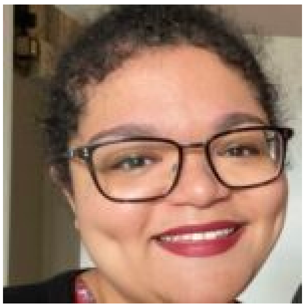


Nagina Khan

Nagina is a Senior Clinical Research Fellow in Primary Care, Centre for Health Services Studies (CHSS), Division of Law, Society and Social Justice, School of Social Policy, Sociology & Social Research, University of Kent. Nagina's current research supports the Integrated Care Systems (ICS) to capitalise on emerging existing networks in its research duty and mitigate the current risk of future research being conducted in silos and without focus on priorities and underserved populations. This work will diversify the public voice listened to and strengthen ICS strategic links within local research infrastructure to support evidence-based practice, apply solutions, and spread innovation. Nagina was a Senior postdoctoral researcher, in CHiMES, Department of Psychiatry, Oxford University. Nagina's research was focused on social justice, equality, and fairness, in culturally appropriate mental health care and complex interventions. She carried out the staff data analysis of Experience based investigation and Co-design of approaches to Prevent and reduce Mental Health Act Use: (CO-PACT) study. Nagina has worked as a Scientist at Centre for Addiction and Mental Health (CAMH) on the mixed method study focused on the Cultural adaptation of CBT for Canadians of South Asian Origin. During the Covid-19 Pandemic, She has also worked with Touro University Nevada, Las Vegas, on Professionalism in undergraduate medical Education and with the Royal College of Psychiatrists on Social Justice, Differential Attainment and Microaggressions in healthcare and medical education. She was a Medical Research Council (MRC) Research Training Fellow, her research was centred on complex interventions for people with depression, University of Manchester. Her post-doctoral studies were also undertaken at the NIHR School for Primary Care Research, UK focusing on First episode Psychosis in Young People Using Early Intervention services. Other research interests include Incentivisation Schemes (P4P) in healthcare for HICs and LMICs and Global Health. Nagina is the Associate Editor at BMJ Mental Health, and she is an Editorial Fellow at BMJ Leader.

More posts - Website

Follow me here –



Nina Higson-Sweeney

Nina is a Lecturer within the Department of Psychology at the University of Bath, and a Postdoctoral Researcher within the Department of Experimental Psychology at the University of Oxford. Her research interests are predominantly within child and adolescent mental health, particularly in the context of depression, anxiety, and OCD. She is also interested in lived experience perspectives, co-production, and favours qualitative methods (although has experience with mixed methods). Nina is one of the blog coordinators at The Mental Elf, focused on commissioning and editing blogs on topics such as youth mental health, digital mental health, and depression.

More posts - Website

Follow me here –

Profile

Sign in with Twitter

Sign in with Facebook

OR

Comment

Name

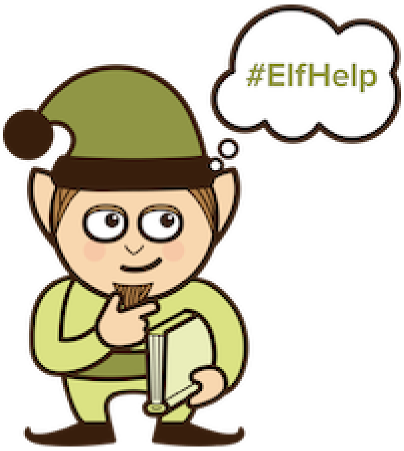
Email

Not published

Website

Post It

re You A Researcher?



We can help you share your findings too — find out how.

The Mental Elf

From Trauma to Trust: a Journey in Psychotherapy.

Share + Follow Acast

June 4, 2025 • 24 min • Listen later

View terms

Recent Posts

Widening the lens on delusions: a global meta-analysis shows our scales miss many common themes

The Lancet Commission on self-harm: a global call for compassionate, culturally informed care

Therapy through the lens of autism: what helps autistic adults feel safe and supported?

Prescribing in borderline personality disorder: Evidence, relationships, and the realities of practice

Who gets included in psychedelics research? A systematic review of ethnoracial representation

Recent Comments

Equineguidance on Neigh to PTSD: can horses help veterans heal?

Iain Ledgerwood on The other side of postnatal depression: what about Dads?

Chy Ogamba on Evidence-based safe staffing levels on mental health wards: there’s no such thing

Free newsletter

Suggest a paper

Do you have a suggestion for a paper? Then let us know.

Click here

Watch our 2 minute promo video!

Commissioning **Dentistry** **Education** **Learning Disabilities**

Mental Health **Musculoskeletal** **Social Care**

Search National Elf Service

Free email newsletter

Enter your email addre

SUBSCRIBE

FOLLOW the Mental Elf