

Background/Aims

- Equality and diversity in clinical research participation is a global issue, and patients that are actively involved in research studies do not always reflect the general population.
- Without inclusive research it is not possible to generalise research findings and understand how different groups respond to interventions.
- Previous research has identified groups within the population who are underserved in clinical trials and reasons for this are complex.
- There are no legal requirements in the United Kingdom with regards to diversity in research. However, the principle of appropriate research access for underserved groups is supported by the Equality Act 2010 and the Declaration of Helsinki.
- Equitable access to the healthcare system and clinical trials is imperative to ensure that research in the Greater Manchester Region (GMR) is inclusive and represents its diverse population.

Aim: The aim of this work is to understand awareness of research diversity among research staff in the GMR and to identify potential strategies to address the issue.

Methods

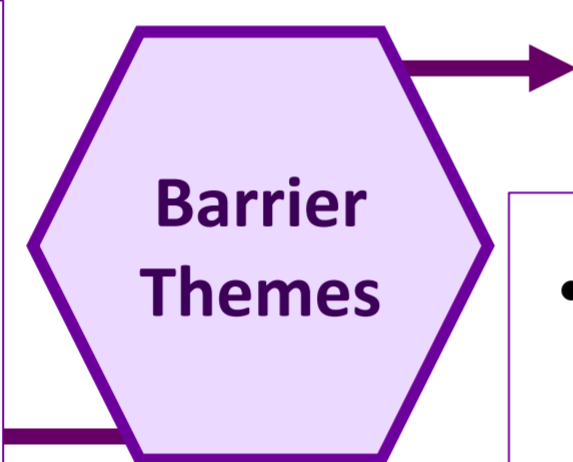
- A survey was distributed to research staff (clinical and non-clinical) within the NIHR Greater Manchester Clinical Research Network (NIHR-GMCRN).
- NIHR-GMCRN consists of 14 local NHS Trusts and 11 CCGs across 30 specialty areas.
- Quantitative and qualitative approach with closed and open questions.
- Conducted online using the Qualtrics platform.
- Respondents were not required to answer all of the questions.



Results

- Of 114 respondents, 37% disagreed or strongly disagreed with the statement that research is inclusive at their NHS Trust/CCG.
- 42% of respondents are being provided with or signposted towards 'diversity in research' training, whilst 36% are not receiving or being directed to any resources.

Survey users were asked to identify the key barriers to research at their Trust/CCG. 194 barriers were submitted and these were grouped into four key themes. The majority of barriers provided related to the way in which research is designed (41%).



Patient

Practical

Community

Research Design

- Some of the main barriers identified (figure 1) related to: language and a lack of readily translated research documents; difficulties in travel and the burden of extra visits; a general lack of understanding about research within the community; and a lack of staff available to adequately support clinical trials.
- 46% of the respondents were unsure whether any strategies had been implemented to break down diversity in research barriers.
- Respondents were invited to provide comments on diversity in research (figure 2).

Figure 1: Breakdown of barriers to research participation in the GMR.

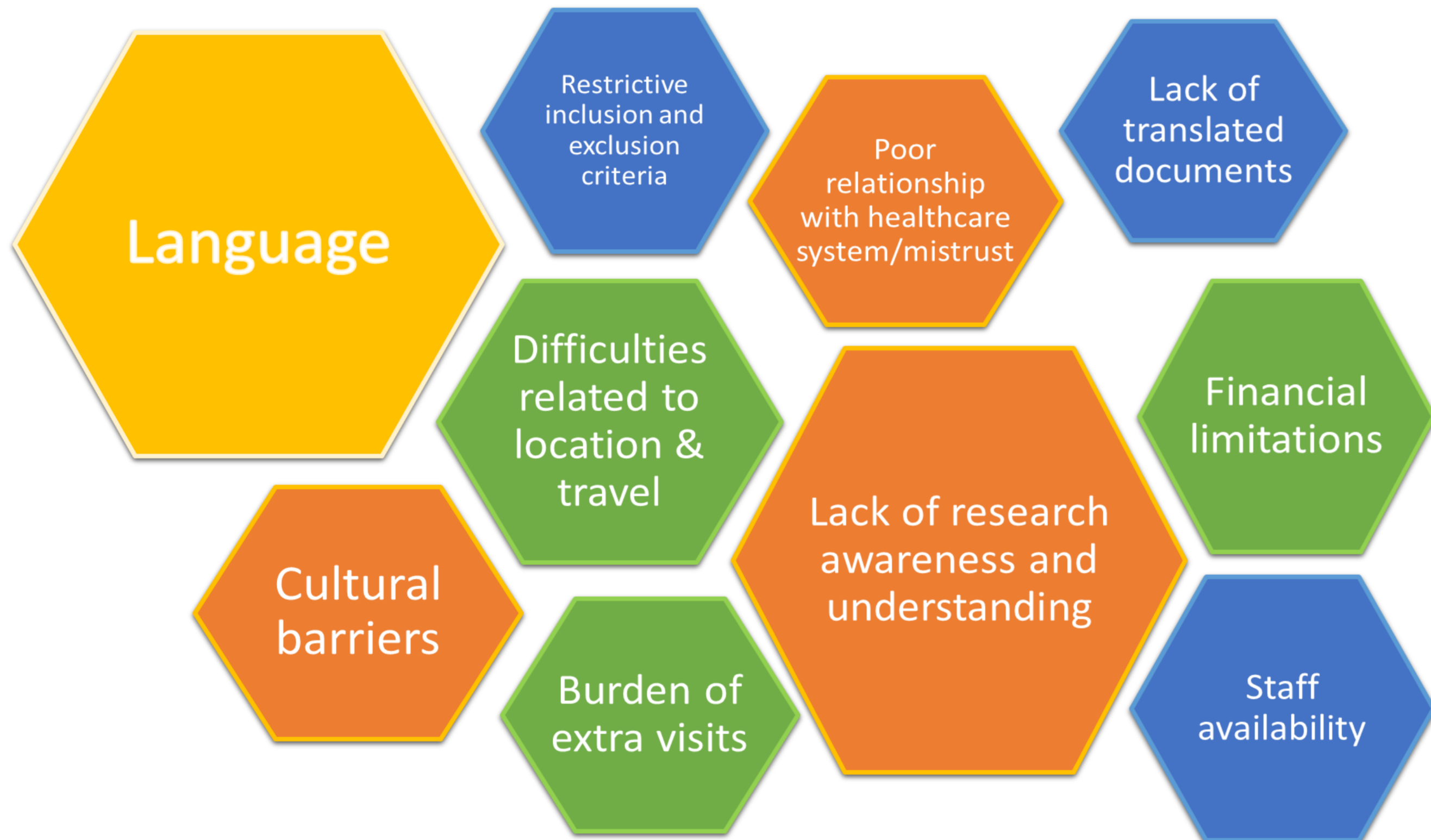


Figure 2: Comments and strategies to overcome the lack of inclusivity in clinical research across the GMR.

"Language is the biggest barrier. It should be standard that all trials can offer translated study documents or finance a translator unless there is a very good reason not to."

"More needs to be done in the community to explain what research is and how it can help."

"Equitable access has to be embedded throughout the research process"

"Researchers should involve patient advisory groups when designing research."

"It is easy to pay lip service to the inclusion and diversity agenda without having any clear metrics to evidence delivery...we need to apply clear benchmarking/metrics and appropriate tools to measure the outcomes of any spend on changing inclusion and diversity of participation within clinical trials."

"It is extremely challenging once a trial reaches the delivery stage to influence this [diversity]. I feel continued work is necessary around the trial design stage, placing greater responsibility on sponsors to consider inclusion and diversity."

Conclusions

With regards to diversity in research in the GMR there are many barriers to overcome, and research in the region should ensure that inclusivity is considered during the design stages, and that funders are supportive of this. Staff within the NIHR-GMCRN also highlighted language, a lack of translated research documents, and poor community-wide understanding of research as some of the key barriers to participation in the GMR.

Potential and actionable solutions to improve research inclusion and diversity in the region include:

1. **Translation:** Improve access to translated study documents. Embed and budget for translation during study design. Co-produce study documents with patients and community advisors to ensure they are culturally appropriate and linguistically accurate.
2. **Interpreters:** Consider identification of bi-lingual staff with research experience within local Trusts who can provide translation services when formal NHS services are unavailable and may result in the exclusion of patients who do not speak English.
3. **Demographic data and outcome assessments:** Identify a demographic dataset to be used across all research in the GMR to achieve consistent and standardised reporting. Formally assess the outcomes of implemented strategies.
4. **Staff training and resource signposting:** Engage with researchers and research staff to continually highlight key resources and training opportunities available.
5. **Collaboration:** Engage, liaise with, and disseminate findings to other groups within the GMR who have an interest or work in this area to share learning and experience.