

The National Institute for Health and Care Research (NIHR) Manchester Biomedical Research Centre (BRC) and NIHR Manchester Clinical Research Facility (CRF): Inclusive Research examples

Case Title	Hearing Health: indicators for inclusive research
BRC Cluster(s)	Under-researched Conditions
BRC Theme(s)	Hearing Health (HH)
Inclusive Research Element	Advice on indicators of inclusivity and ethics processes
Rationale for case study	Across all work in the Manchester BRC, there is a need for both inclusivity in research design related to participation (including methodological approaches) and monitoring of participation in research (usually anonymous questionnaire-based). The Hearing Health Theme are encouraging all research projects to collect data about a set of protected characteristics for Equality Diversity and Inclusion (EDI) / Inclusive Research (IR) monitoring (participants in research) to help improve the applicability of the results of the research to be applicable to the widest number of different people.
Background	Hearing Health EDI leads had created a document covering a suggested standardised process for collecting protected characteristics data to help monitor who is getting recruited to take part in research. They had also developed a Qualtrics Questionnaire (to enable collection of anonymous information about people who take part in Hearing Health research studies). However, it has been hard to get uptake from all researchers, especially as there have been some cases where ethics committees questioned the need to collect these data and have sometimes provided inconsistent feedback on applications, which in turn has led to some reluctance of researchers to add it to their applications. Hearing Health wished to gain help in creating 'standard' text for explaining the importance of collecting indicator data which could be used in future ethics applications and on engaging with governance staff (University of Manchester ethics) to help them better understand the importance of Inclusive Research and why it was important to collect such information.
What we did	The Inclusive Research Team provided initial advice around the standard processes recommended by the Inclusive Research Oversight Board (IROB) for collecting anonymous data unlinked to specific projects (as set out by NIHR), indicators to be chosen for non-anonymised monitoring and the ethics process (via email and meetings). This has been updated since the changes NIHR made to question wording in May 2024.
What the outcome(s) is/are	EDI lead (HH) is monitoring results of indicator data and has presented back to HH colleagues, BRC Exec and IROB. Looking to tweak questions as appropriate for studies. Recently finding few issues successfully getting the questionnaire approved by ethics.
Conclusions	This will be an issue affecting themes and clusters wider than just Hearing Health, so working through the process together could suggest a way forward in the longer term for all BRC researchers.
Recommendations	IROB recommends using the NIHR Workforce Questions (updated May 2024) for anonymised non-linked monitoring where the collected information will be kept and managed separately from data collected and confidentially of EDI indicators amongst the BRC and CRF study participants.
Future work	Working with University governance (ethics) and others to understand the outstanding methodological issues and potential blockages in the ethics approval system. HH looking to standardise the questions asked (wording).