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	Rheumatic and Musculoskeletal diseases: Inclusivity indicators
BRC Cluster(s)	Inflammation Cluster
BRC Theme(s)	Rheumatic and Musculoskeletal Diseases
Inclusive Research Element	Indicators of Inclusive Clinical Research
Rationale for case study	In all Manchester BRC work, there is a need for both inclusivity in research design related to participation (including methodological approaches such as from Inclusive Research team methodologists and PPIE input) and monitoring of participation (usually anonymous questionnaire-based). The Rheumatic and Musculoskeletal Diseases (MSK) theme encourages all researchers to collect data about protected characteristics to ensure the equality and inclusivity of study participants in MSK research projects and comply with the Equality Diversity and Inclusion (EDI) strategy under the BRC.
Background	The Health Inequalities Steering Group inspired the work to monitor the demographics of engagement and involvement in studies. Under the BRC and CRF Inclusive Research Infrastructure, much work is done to monitor demographic involvement and engagement (Patient and public involvement, engagement (PPIE)) in close collaboration with Vocal. Lessons can be learned from these steps. For example, the research project Biologics in Rheumatoid Arthritis Genetics and Genomics Study Syndicate (BRAGGSS) got ethics approval for a demographic form for participation monitoring by utilising the NIHR Questions for workforce monitoring. The form includes questions on socio-economic indicators (first part of the postcode and education level), disability, gender, marriage and civil partnership, pregnancy and maternity status, caring responsibilities, ethnicity, religion or belief, sex, and sexual orientation. This section was added to the BRAGGSS Baseline Patient Questionnaire.
What we did	An Inclusive Research Team member attended the meeting in June 2023, where experts on the patients and public engagement from Vocal, BRC, and CRF were present. The meeting's agenda was to discuss gathering EDI data in the MSK BRC theme (and beyond). The point of discussion was the need to relate existing and emerging learning and practice about participation monitoring to the requirement from NIHR for diversity data. A key suggestion was to explore how inclusivity in design and participatory research can account for many more complex factors than participation monitoring, including, for example, the social construction of ethnicity and protected identities. The Inclusive Research team member met with Dr Andrea Murray to discuss how the team could contribute to building good practices related to monitoring participation. After learning from the BRAGGSS Baseline Patient Questionnaire template and ethics application amendment notes, the Inclusive Research Team member worked on the indicator report.
What the outcome(s) is/are	A case study around learning, related to the monitoring of participation was proposed with the view of sharing it with other BRC themes and the CRF. The first literature review reported to the BRC/CRF Execs was in 2023 and as this is a working document with new evidence being added, it will be reviewed in September 2024 and the updated report will be circulated.
Conclusions	The finalised case study will be shared with other clusters and themes within the Manchester BRC to serve as a guide to collect data on protected characteristics. This will help researchers have a better understanding about populations who participate in research/demographics of BRC studies and monitor the impact of the Inclusive Research Team methodologists and PPIE input.
Recommendations	IROB recommends and encourages researchers within the Manchester BRC (all Clusters/Themes) to collect data on protected characteristics in their studies.
Future work	To share the case study around learning related to the monitoring of study participation once finalised. To meet with the various Cluster/Theme leads to encourage the collection of protected characteristics data and its importance