NIHR | Manchester Biomedical Research Centre

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

Title	Understanding the factors that influence recruitment to a UK national rheumatology cohort study: a discrete choice experiment
BRC Cluster(s)	Inflammation
BRC Theme(s)	Rheumatic and Musculoskeletal Diseases
Inclusive Research Element	Methodological: stated-preference survey using a discrete choice experiment
Rationale for case study	To understand what factors, influence healthcare professionals to recruit an individual with moderate to severe rheumatoid arthritis (RA) to an exemplar national rheumatology cohort study, the British Society for Rheumatology Biologics Register – RA (BSRBR-RA). To use these factors to explore if the current recruitment strategy for the BSRBR-RA can be modified to enable uptake across specific groups in society such as people from different ethnicities and socioeconomic groups.
Background	Biological medicines (hereafter 'biologics'), designed to target components of the immune response, have been shown to be highly effective as treatments for moderate to severe rheumatoid arthritis (RA). Recommendations for using biologics and their biosimilars ('copy' of an existing biologic) have been produced for clinicians working in the NHS. The first of these, anti- Tumour necrosis factor (TNF) therapies, was approved by NICE in 2002 and since then, multiple other classes of biologics have been approved. Most recently, a new class of targeted therapies, the Janus kinase (JAK) inhibitors, have been approved and in regular use. These advanced therapies (biologics and JAK inhibitors) are recommended as treatment options for adults with RA if therapy with 2 or more conventional synthetic disease-modifying antirheumatic drugs (csDMARDs) has not controlled the disease well enough and the disease activity score [DAS28] remains high. In 2001, a collaboration was established between The University of Manchester, the British Society of Rheumatology (BSR), and many relevant pharmaceutical companies which market biologics to begin a prospective longitudinal cohort study recruiting people with RA starting biologics, or more recently JAK inhibitors during routine NHS care, with the primary goal of monitoring their real-world effectiveness and safety (the BSR Biologics Register for RA (BSRBR-RA). Since its inception, the BSRBR-RA has registered ~ 30,000 people. Patients are recruited directly from NHS rheumatology clinics, where consent is taken from the patient to join the register after a decision has been made to start a biologic. Recently, as part of a research programme led by the University of Manchester, an examination of the data revealed that there may be significant imbalances in who is being recruited to the biologics register, regarding their social position or ethnicity. For example, only 3.9% of patients in the sample recruited between 2002 and 2008 were non-white whilst it would be expected, based on UK census data that 18% of the UK population identify as non-white. There is no evidence that susceptibility to RA is related to ethnicity. Understanding what drives preferences about who researchers decide to approach and recruit to a study such as the BSRBR-RA, may help understand observed differences in the proportion of people from non-White backgrounds as well as differences across other patient demographics.
What we did	A stated-preference survey, using a discrete choice experiment (DCE), will be designed and sent to a sample of healthcare professionals (target responses~300) who are actively recruiting people to an exemplar national cohort study (BSRBR-RA from one of the 113 sites). The DCE will be framed around understanding why health care professionals choose to recruit people to the BSRBR-RA as a result of starting them on a biologic for moderate to severe RA. The choice question will be piloted but an indicative question to be framed is: *would you choose to approach this individual to enrol them on the BSRBR-RA?*

What the outcome(s) is/are	Regression methods will be used to analyse the choice data collected from the DCE. The attributes in this DCE will likely be qualitative. The results will therefore be presented as an estimated predicted recruitment to the 'BSRBR-RA' using scenarios of exemplar 'patients. These exemplars will be defined by assumptions about which level is assigned to each attribute used in the DCE design. These results will then be used to inform potential strategies to encourage recruitment to the BSRBR-RA using an expert consensus meeting.
Conclusions	None to date; work ongoing
Recommendations	None to date; work ongoing
Future work	This work is not completed. Future work will present the results of this survey to understand which factors influence clinicians to recruit people to the biologics register to inform strategies to encourage inclusive recruitment.

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