

Patient and public involvement in Rheumatology research – embracing the wave of change

Su-Ann Yeoh BMBS(Hons)¹, Barbara Burke MBA^{2,3}, Madhura Castelino PhD¹, Tracy Hyndman MN^{1,3}, Anne-Maree Keenan PhD⁴, Sue Watson^{3,4}, Laura C. Coates PhD²

1. Department of Rheumatology, University College London
2. Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford
3. Patient research partners
4. NIHR Leeds Biomedical Research Centre, University of Leeds and Leeds Teaching Hospitals Trust

Corresponding author:

Laura C Coates

Botnar Research Centre

Windmill Road

Oxford, OX3 7LD

UK

Tel: 01865 737838

Email: laura.coates@ndorms.ox.ac.uk

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Patient partnership in research is crucial to ensure that research priorities align with the priorities of patients. There are various ways in which patients can be integrated into research.¹ Three facets are important to ensure successful, patient-centred research—patient involvement, patient engagement, and patient participation. All three require a long-term investment to nurture patient and researcher/clinician relationships, supported by resources developed by organisations such as INVOLVE, a national advisory group funded by the National Institute for Health Research (NIHR) which supports public involvement in research.¹ While patient and public involvement has been shown to promote higher standards of research² and improve patient outcomes,³ there is a need for enhancing the consistency, quality, and frequency of activities around patient and public involvement.⁴

Patient and public involvement is particularly crucial in rheumatology research, as most rheumatic and musculoskeletal conditions are life-long and life-altering. To foster high quality, patient-focused research and ensure that patient and public involvement activities have a positive impact on research, patient and public involvement should be undertaken in a structured manner, guided for example, by the UK Standards for Public Involvement.⁵ The beneficial effects of patient and public involvement on health research have been reported, not only from the researcher perspective⁶, but also from the patient and public perspective^{6, 7}, where patient and public involvement have been described to positively influence the research process from the initial stages of research with the development of research questions, research design and delivery, data collection and analysis, through to dissemination.⁸ In addition, patient and public involvement has been described to have a positive impact on enrolment to research studies, as reported in a systematic review and meta-analysis⁹.

Rheumatic conditions and therapeutics can rapidly evolve and world events, such as the COVID-19 pandemic, can bring unanticipated issues and new research priorities that require appropriate and timely responses that are best facilitated through established frameworks, supported by academic institutional infrastructure. Here, we detail the experiences and patient and public involvement models of three academic centres in the UK.

The NIHR Leeds Biomedical Research Centre patient and public involvement group was established in 2010 and is supported by a Manager and an Outreach Officer. The group has over 250 people comprising patients, carers, and members of the public, whose activities are overseen by a Core

Group of ten experienced members within an established infrastructure, including bi-monthly meetings, task and finish working groups and membership of the Biomedical Research Centre's Board, central to research prioritisation, development, conduct, and review across the centre. A key aim of the group is to support activities involving under-represented groups and to promote greater diversity, underpinned by a strategy which focuses not only inclusive communication, but on taking activities away from the hospital and into appropriate community settings. In response to COVID-19, patient and public involvement activities were temporarily moved to a virtual format, resulting in increased engagement as well as the opportunity for members to engage with and contribute to COVID-19 research and vaccine studies.

University College London (UCL) has set up Patient Partners in Rheumatology Research, launched in 2020 and supported by UCL NIHR Biomedical Research Centre. Inspired by the dynamic patient and public involvement scene in adolescent and young adult research coordinated by the Centre for Adolescent Rheumatology, the aim of the group is to foster a more structured approach to patient and public involvement in adult rheumatology. Patients and researchers were surveyed, and focus group meetings were held to identify a patient and public involvement model that best suited the requirements of both groups. The model developed is that of a core patient and public involvement cohort representing various rheumatic conditions who will provide input during virtual meetings, with discussion around research project development and priority setting. Review of patient-facing literature, funding application documents, study paperwork, and research reports is a key activity to ensure that materials are written in language that is understandable to the general public. Training events and focus groups have been held virtually for patient partners with a view to boosting patient engagement and participation, but will likely transition to a hybrid in-person/virtual model once COVID-19 restrictions are no longer in effect.

Oxford Biomedical Research Centre has a large and successful advisory group overseeing patient and public involvement across all specialities; within the musculoskeletal theme, patient and public involvement has historically involved small disease-specific groups. In 2020, the musculoskeletal theme started to establish a new theme-wide patient engagement group, the Oxford Patient Engagement Network in Arthritis and Musculoskeletal Science (OPEN ARMS) group, with an aim to focus on diversity and gain representation from previously harder-to-reach groups. To support this aim, recruitment materials have been developed with significant patient input and has involved extensive outreach to different community groups. Although this proposal was conceived prior to the COVID-19 pandemic, the majority of the work to date has been successfully run remotely, and different community groups have been targeted for patient representative recruitment in 2021.

Success will be audited via a framework applied to future studies done at the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, evaluating patient and public involvement at all stages including design, implementation, analysis, and dissemination.

Whilst the approaches described here are crucial to local research activities, it is also essential to have patient-centred national and international priority setting for research, for example, the James Lind Association Priority Setting Partnerships. These processes are run by small committees of researchers, clinicians, and patients interested in a particular topic (or disease). The team request proposals of research questions via survey targeting patients, families, carers, and clinicians working in the field. A second survey then asks respondents to rank these in a priority list. A workshop then produces a final top ten of research priorities, allowing researchers and funders to identify key questions for future research. A priority setting partnership addressing psoriatic arthritis is currently underway and is funded by the British psoriatic arthritis consortium (BritPACT).

The patient and public involvement groups have seen different challenges posed by running virtual events depending on the length of time the groups have been established. Well-established groups, such as in Leeds, may have found the transition to virtual platforms much more streamlined, guided by pre-existing infrastructure. However, it has been observed that this move to digital platforms has had an adverse impact on diversity and participation from under-represented groups due to variable technology proficiency, access to technology, ability to advertise events, and a lower representation from older age groups. Newer groups, such as UCL and Oxford, have been set up on virtual platforms from the outset due to the pandemic. A benefit of this is participation from busy individuals due to the removal of travel time. However, this limits the ability for patient partners to get to know each other in an informal manner (mitigated by small-group “break-out” discussions by UCL) and restricts participation from people who do not have easy access to the internet. It is likely that future patient and public involvement events will return to having an in-person element, either as entirely face-to-face events or a hybrid format of virtual and face-to-face. The advantages of virtual meetings will not be overlooked and will be useful for planning meetings and also reaching the younger demographics, such as adolescent and young adult patients.

Patient involvement in rheumatology research is vital due to its benefits to researchers, clinicians, and patients, and should be carried out in a structured manner. Unprecedented challenges such as the COVID-19 pandemic has resulted in a transformation in the conduct of PPI activities and priority setting partnerships. Adapting virtual platforms has revolutionised PPI activities during COVID-19, but we should be mindful that our efforts remain inclusive with patient representation from a range

of demographics to ensure that the research focus represents the wider community whilst continuing to apply innovative thinking to ways to develop dynamic, impactful collaborations with patients.

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Authors' contributions

SAY produced the first draft of the article. BB, MC, TH, AMK, SW and LC contributed equally to review, writing, and editing the article.

Declaration of interests

AMK is Deputy Director of the NIHR Leeds BRC and an NIHR Senior Investigator.

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