

Patient and public involvement in the National Early Inflammatory Arthritis Audit (NEIAA)

The National Early Inflammatory Arthritis Audit (NEIAA) has been commissioned to understand and improve the quality of care for patients over the age of 16 with inflammatory arthritis across England and Wales. NEIAA includes strong collaboration with patients, as well as healthcare professionals and aspires for a service that puts the patients needs first.






How are patients involved?

Since the establishment of the audit in 2018, the Patient Panel has been instrumental in helping deliver patient-focused outputs in the project. The Patient Panel generally meets twice a year (including remotely) and works closely with the NEIAA Project Working Group (PWG). The panel Chair, Vice-chair and Co-ordinator attend quarterly PWG meetings. In addition, the Co-ordinator attends quarterly Senior Governance Group (SGG) meetings.

Representatives from patient-focused national charities (National Rheumatoid Arthritis Society (NRAS), National Axial Spondyloarthritis Society (NASS) and Arthritis Research UK) also attend SGG meetings, thus ensuring wider patient involvement.

2022 Activities

This year, the Panel's work has been centred around the development of the following publications:

-  Annual NEIAA 2022 patient and public report
-  The NEIAA ethnicity report
-  A study, focused on the NEIAA ethnicity data
-  Patient-led clinic visit framework report, submitted to *BMC Rheumatology*
-  NEIAA's re-tendering document

Accessibility of information for patients and carers

Working with the Patient Panel and national charities enables the NEIAA team to produce documents which aim to be relevant, free from medical jargon and easy to understand and follow. Alongside the upcoming fourth annual NEIAA Report 2022, a patient and public version is also co-produced, which ensures that appropriate language is employed and any quality improvements priorities are agreed with patients. The national charities on the SGG are also involved in reviewing and providing feedback on the NEIAA draft reports.

Audio format, for those unable to read or who are visually impaired, is being explored for this year's Patient and Public Report.

NEIAA Communication Channels

[NEIAA Website](#)[NEIAA Newsletter](#)[Patient and Public Annual Reports](#)[BSR Communication channels \(e.g. webinars and podcasts\)](#)[Presentations of the audit findings in webinars and at BSR conferences](#)[National Patient Charities \(NRAS and NASS\)](#)

Impact

The NEIAA Patient Panel played an influential role on the study of the relationship between ethnicity and the processes of care and outcomes, in a cohort of patients recruited to the NEIAA between May 2018 and March 2020.

Published in January 2022, the NEIAA report on ethnicity highlights that patients from ethnic minority backgrounds, though younger and less likely to smoke, still showed less improvement in disease activity scores compared to their Caucasian counterparts (30% vs 37%) and had worse mental health outcomes (33% vs 30%).

“As someone who is mixed race, I’m concerned about the findings and wonder why there are these disparities. My experience mirrors the findings in this report... all these issues around inconsistent care, varied outcomes and lack of participation need addressing. As we look to the future, it’s crucial that we strive for equal care for everyone.”

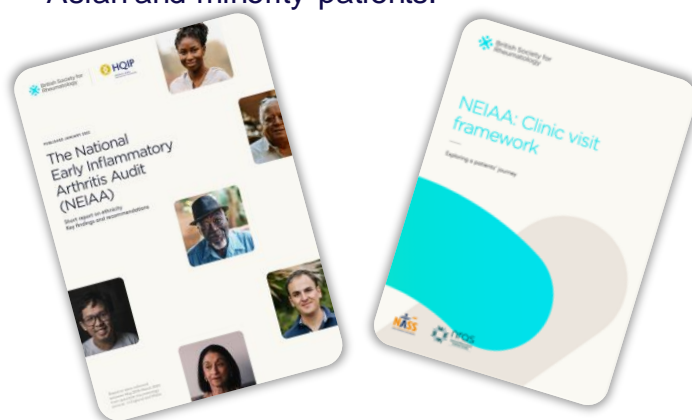
Tom Esterine, a 60-year-old musician from London and a patient panel member



Based on the findings of the ethnicity report, the Patient Panel co-produced a national cohort study, analysing data for over 35,000 patients and assessing variability in care quality and treatment outcomes across ethnicities in early inflammatory arthritis. It was published in May 2022 and can be found at:

<https://pubmed.ncbi.nlm.nih.gov/35536178/>

These reports aim to empower the stakeholders to use the data to facilitate improvements in the quality of care for black, Asian and minority patients.



Furthermore, a Patient Panel co-produced manuscript has been submitted to the BMC Rheumatology journal for publication for a themed call on Patient and Public involvement in March 2022. This case study focuses on the development of a patient-led clinic visit framework, detailing how the patient panel worked with NEIAA governance groups and the national charities (NRASS and NASS) to co-create an outpatient clinic visit framework for patients and rheumatology professionals. The original ‘NEIAA: Clinic visit framework’ was published and made available last year by BSR, which outlines points for consideration prior to, during and after patients’ outpatient appointments. It is also included in the teaching of undergraduate students at King’s College London Medical School.

Moreover, the Patient Panel has also contributed to NEIAA re-tendering document, by feedback and co-production of audit outputs.

Sustainability

NEIAA ensures that people with lived experiences of inflammatory arthritis influence the work to drive improvements. The panel discussed exploring further areas of improvements, specifically in:

- Expanding dissemination of information via NHS Directory, NHS websites and GP practices, and closer work with national charities. For example, working with NRAS to raise the profile of the NEIAA and to encourage participation in taking part via its New2RA Right Start programme
- Ensuring the audit results are more widely distributed from Trust level to local rheumatology department and rheumatology outpatient areas
- Enabling patients to access data about their healthcare provider to promote further service development
- Recruiting patient champions, to engage with the local services to raise profile of the audit
- Supporting the public affairs team at BSR in getting the messages of NEIAA out to the key stakeholders

Conclusion

The Patient Panel will remain instrumental for the success of NEIAA, ensuring that the outcomes focus on topics relevant to service users. It is evident from the publications produced by the Patient Panel that patients, with lived experiences can contribute effectively to the development of resources for recipients and providers of care and is key in any service development and improvement.

