British Society for Rheumatology

HQIP
Healthcare Quality Improvement Partnership

Patient and Public Involvement in a National Audit through the COVID-19 pandemic

Introduction to the National Early Inflammatory Arthritis Audit (NEIAA)
NEIAA is a complex audit requiring data capture from clinicians and patients at “baseline” (when a suspected diagnosis is first assessed), then after three and 12 months of follow up for patients with a confirmed diagnosis of rheumatoid arthritis (RA). The audit assesses compliance with The National Institute for Health and Care Excellence (NICE) quality standards as well as clinician and patient reported outcomes.

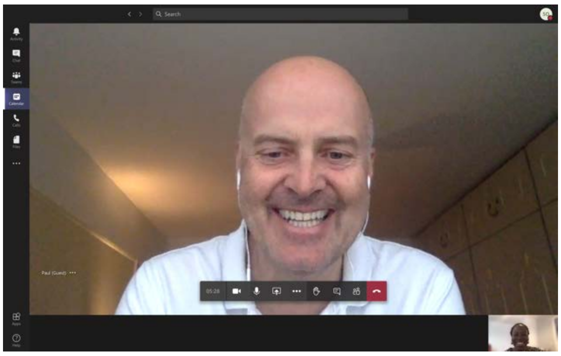
Challenges to the audit before and during the COVID-19 pandemic

NEIAA captures information about care quality in NHS rheumatology outpatient services. These services were suspended at the outbreak of the pandemic. A substantial proportion of rheumatology clinical staff were redeployed to manage COVID-19 wards (including members of the NEIAA operations team). Although services are now resuming and staff have returned to usual roles, a majority of patient contact now happens remotely rather than face to face.

The COVID-19 pandemic has uniquely challenged patient and public involvement in NEIAA; the audit is supported by an engaged group of nine individuals with rheumatic disease who have contributed to the design of NEIAA, and interpretation and dissemination of findings. The nature of rheumatic disease treatment, using medication that suppresses the immune system, has meant our patient panel were recommended to shield by the UK Government during the pandemic.

Supporting continued patient and public engagement

The NEIAA Patient Panel is an independent panel of patients that meets regularly and feeds back to the NEIAA operations team, project working group (PWG) and senior governance group (SGG) meetings via their chair, vice-chair and patient panel coordinator. The Patient Panel has received support from the NEIAA operations team in adapting to online meetings and this panel has successfully completed tasks started prior to the COVID-19 pandemic and has continued to actively contribute to outputs and changes to NEIAA.



Patient Panel Chair, Paul Amlani-Hatcher, during a video call with the Project Manager, Sarah Oyebanjo

All scheduled NEIAA meetings have continued remotely and attendance has been excellent. Patient organisations and representatives have continued to contribute to the quarterly PWG and SGG.

Achievements of the patient panel: (1) designing a COVID-friendly EIA service

The Patient Panel has drafted an 'ideal clinic visit' document detailing factors of importance to patients when attending rheumatology services. This was a recommendation from the NEIAA first annual report. The document is under review with the PWG and will be published to service providers soon.

Included in this document is a patient perspective on:

- How to optimise remote early arthritis consultations for patients
- Technology considerations and how to select people for remote review
- Face-to-face consultation practicalities
- Infection control considerations, a service user's view
- Information to provide prior to a first appointment
- Recommendations for literature for waiting rooms

The report was adapted specifically to address the challenges of COVID-19. The work was completed by email communication and virtual meetings. It was solely directed by the Patient Panel who agreed on the overall structure and scope of the document. The chair and vice-chair of the Patient Panel worked closely with National Rheumatoid Arthritis Society (NRAS) and National Axial Spondyloarthritis Society (NASS) and ensured that the framework aligned to up-to-date information provided by both national charities.

Achievements of the patient panel: (2) Supporting quality improvement despite COVID

In addition to the ideal clinic visit framework, the Patient Panel has actively contributed to the NEIAA quality improvement (QI) plan (completed in July 2020 with specific plans for patient and public involvement in QI activity detailed within it) and to the second (full and linked patient and public) annual report which is due to be published early next year. The Patient Panel has provided constructive feedback on the year 2 full annual report, ensuring use of lay language and inclusion of comprehensive information relevant to patients and the public. The linked patient and public report has been produced by the Patient Panel.

Achievements of the patient panel: (3) supporting online education for clinical teams

The Patient Panel chair has also contributed to webinars attended by clinicians as a means of publicising the NEIAA and its importance to patients. This involvement was arranged as a priority, considering the forced cancellation due to the COVID-19 pandemic, of the British Society for Rheumatology (BSR) annual conference where this presentation was originally planned for a main conference session. Feedback has reinforced the value of this patient perspective in promoting the audit.

Achievements and changes to the audit data collection processes

The data collection processes for the audit have changed in light of the COVID-19 pandemic. The Disease Activity Score (DAS) is one of the most important outcome measures in the audit. This is a composite measure that includes counting the number of tender and swollen joints a patient has. The DAS is collected by clinicians during a face-to-face appointment.

NEIAA worked with NRAS and the patient panel to develop an online version of the

DAS, with patients counting their own tender and swollen joints. The new module was added to the patient portal in April for testing by the patient panel and then launched for widespread use in June.

The NEIAA operations team have conducted a rapid review of the evidence base in parallel to confirm the validity of patient reported DAS, and the results of the review have been communicated to NEIAA users through two educational webinars.

The use of such patient derived data has been validated and this initiative is proving successful in maximising data capture on outcomes over the first year of specialist care.

The decision to set up a separate patient website for NEIAA to allow patients to enter data at a time convenient to them was made in consultation with the Patient Panel and has proved a valuable tool for the audit more generally. Through email reminders of when data is due from patients, the audit is capturing patient derived outcome data, including the recent additions of tender and swollen joint counts, from a much higher proportion of patients than in the previous phase of the audit, when this function was not available.

The patient website continues to provide advice and support to patients recruited to the audit, with information and frequently asked questions which are updated when required.

Future plans and summary

A presentation from the Patient Panel chair is approved for a main session within the 2021 BSR annual conference and this will provide further opportunity for the patient voice to be heard, not only by clinicians from the United Kingdom and involved in this audit, but also worldwide.

Patient and patient organisation involvement in QI work using audit data, as detailed in the audit QI plan, will be actively pursued.

In summary, the whole NEIAA team acknowledges the benefits to the audit from the Patient Panel and the three representatives from relevant patient charities that sit on the SGG. Their involvement will continue through email/telephone contact and through remote, or once re-established, face-to-face meetings. One benefit of developing remote meetings is that the burden of long commuting, which at times has been a barrier to patient attendance at face-to-face meetings, can be avoided and can allow members to more reliably contribute to meetings and to all aspects of the audit.