

## **Public and patient involvement in the National Early Inflammatory Arthritis Audit (NEIAA) 2021**

### **Introduction**

The NEIAA collects information on all new patients over the age of 16 with suspected Autoimmune Inflammatory Arthritis seen in specialist rheumatology departments in England and Wales. The audit aims to promote quality improvement in the early management of all forms of inflammatory arthritis (with a specific focus on Rheumatoid Arthritis (RA)) through assessment of patients' clinical outcomes, day-to-day function, mobility, sleep, wellbeing, and ability to work.

### **Role of Patient Panel in the audit**

The Patient Panel includes a group of nine diverse patients and one coordinator who support the NEIAA. Established when the audit started in 2018, the panel brings the patient perspectives throughout all the NEIAA workstreams. The group meets at least twice a year to review and provide comments on specific projects including the annual report and quality improvement plan.

### **Governance including patient involvement**

The patient voice is integral to the governance of NEIAA and this is reflected in meeting attendance. The Patient Panel chair, vice-chair and coordinator attend the quarterly Project Working Group (PWG) meetings and the coordinator attends the quarterly Senior Governance Group (SGG) meetings, thus providing several opportunities to contribute meaningfully to the audit. In addition, representatives from patient focused national charities, National Rheumatoid Arthritis Society (NRAS) and National Axial Spondyloarthritis Society (NASS), attend the SGG meetings and contribute to the audit.

### **Patient involvement throughout NEIAA**

A major success of NEIAA to date has been capture of patient reported outcome (PRO) quality measures (disease impact, work, mental health). A patient portal was built to enable direct data entry from patients and the patient panel were involved in piloting the platform to ensure it was fit for purpose. Feedback on the patient website has been excellent, with data submission rates from patients much improved since the first audit (rising from 15% to over 40% PRO return at 3 months). The Patient Panel also supported the development of the PRO data download tool which reinforces the value of submitting PRO data to patients as well as empowering patients to influence their own care decisions.

Providing information for patients and members of the public in a suitable format is another one of NEIAA's priorities. Alongside the clinician second annual report published in January 2021, a patient and public version was produced. The Patient Panel was thoroughly involved in the development from inception to ensure that their insight was fully gathered and reflected in the final version. Prior to producing the patient and public version of the annual report, the clinician version was shared with the group. This was followed by a skeleton document which the panel contributed to and provided extensive feedback to ensure that the appropriate language was employed. Representatives from relevant patient focused charities on our SGG were also involved in reviewing and providing feedback on the NEIAA draft reports. After

the publication of the report, NRAS included a two-page spread in their newsletter thus broadening the reach of the report to members of the public.

Due to the pandemic, the NEIAA team will not be publishing a third annual report, however, the team will be publishing a report focusing on the link between ethnicity, clinician and patient reported outcomes and achievement of the seven quality metrics set out in NICE (National Institute for Health and Clinical Excellence) quality standard 33 (QS33) for England and Wales. The patient panel were instrumental in deciding on the focus of this report, as it was one of their key priorities for the year. Representatives from the patient panel were involved in reviewing the first draft and provided feedback throughout every stage of report writing. One of the findings from the report is that people from minority groups have worse mental health outcomes. During a meeting to review the report one of the patient panel members shared his experience and this led to a decision to include a case study in the report with the aim of providing further insight into the patient pathway and the importance of addressing mental health. This report will be published later this year.

The data collection process for the audit has undergone several changes and the Patient Panel has contributed to several of these processes. The group was involved in the development of the online version of the Disease Activity Score tool allowing patients to measure the number of tender and swollen joints. This tool helps to ensure that this outcome measure is captured and increases the likelihood of data completeness where patients are unable to attend a face-to-face appointment.

To further support patients with participating in the audit, videos providing information about the audit are available to patients and have been viewed almost 2,500 times to date thus showing their value.

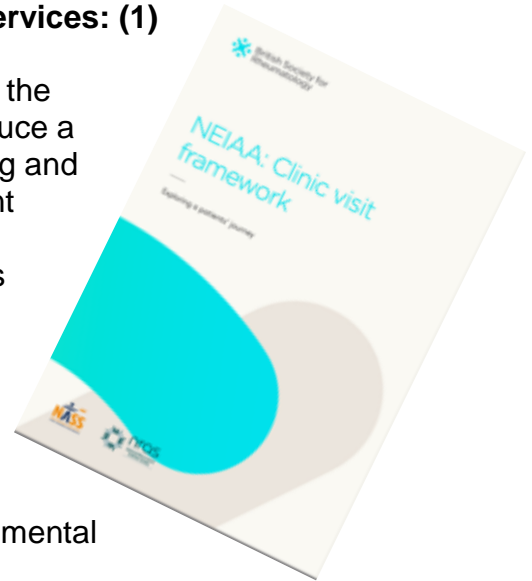
### **Working with patient focused national charities**

NRAS developed a New2RA Right Start programme to supplement clinician provided patient education and in order to support patients with a new diagnosis of EIA. This was piloted by clinicians on the PWG. Additionally, the NEIAA team are currently working with NRAS to create additional videos with subtitles to encourage patients from minority groups to complete PRO forms.

Furthermore, NEIAA has provided further “real world” evidence of a known problem of delayed referral and specialist assessment for patients with axial spondyloarthritis (axial SpA) giving extra impetus to the latest education drive from NASS to try to reduce these delays – the “act on axial SpA” campaign was launched this summer.

**Recommendations for quality improvement in local services: (1) clinic visit framework**

As a result of a recommendation in the first annual report, the Patient Panel worked alongside NRAS and NASS to produce a framework outlining points for consideration prior to, during and following patient’s outpatient appointments. This document will be updated by the patient panel on an annual basis to ensure that the content stays relevant. This document has been shared widely with the rheumatology community via several communication channels. It was the most accessed link in the July audit newsletter. In addition, the framework has been adapted at King’s College London Medical School for teaching undergraduate medical students on how best to care for, and communicate with patients who are diagnosed with a variety of physical and mental disabilities and with their carers.



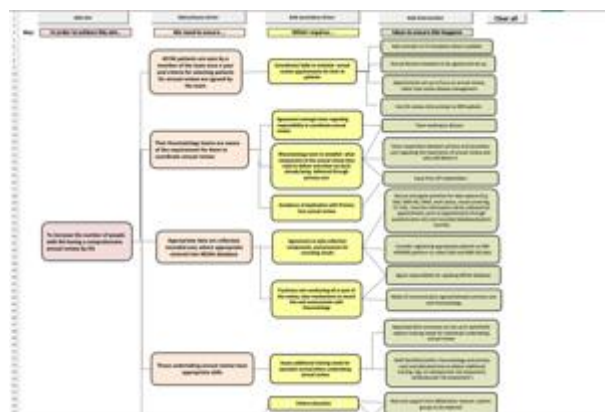
**Recommendations for quality improvement in local services: (2) promoting the audit**

In addition to this, the Patient Panel Chair has contributed to several projects to promote the audit and its importance to patients. As well as presenting at the British Society for Rheumatology (BSR) annual conference and participating in several webinars attended by clinicians, the Chair recorded a podcast for a paper he had co-written on disease activity and its predictors in early inflammatory arthritis.



**Recommendations for quality improvement in local services: (3) developing quality improvement resources**

To support quality improvement the NEIAA team have developed several resources, including driver diagrams. The Patient Panel Chair contributed to the most recent driver diagram for Quality Statement 7, focusing on annual reviews. Latest NEIAA data have highlighted the poor provision of annual review services with huge variation shown across regions. The patient panel have consistently highlighted how important the annual review process is to patients



## **How the audit has supported me as a patient advocate - Paul Amlani Hatcher, Patient Panel Chair**

The NEIAA has offered me an opportunity, as somebody recently diagnosed with Rheumatoid Arthritis, to add my voice and that of other people I am in contact with through NRAS to this amazing audit. As a patient I have also been able to access the data for my Health Provider and gauge their performance, in responding to Inflammatory Arthritis, up against other health providers as well as the quality standards set out by NICE. The audit has also given me a level of knowledge about how Inflammatory Arthritis is being managed nationally and locally that I am able to broadcast through other channels of my volunteering activity in this area of health provision.

### **Summary**

In summary, the Patient Panel plays a fundamental role in supporting the NEIAA team. Their input throughout the audit helps to ensure that NEIAA achieves its aim of improving patient care and of ultimately improving patients' clinical outcomes. The NEIAA is fully committed to involving patients continuously and directly in all the work that it is contracted by HQIP to carry out.