

# HQIP Case Study:

## PPI in national clinical audit – Submission to the Richard Driscoll Memorial Award 2019

### This submission demonstrates:

Working with a patient panel to understand how best to communicate with patients  
Creating innovative videos and a website specifically for patients

**Date:** Richard Driscoll Memorial Award – Autumn 2019

**NCAPOP:** [National Early Inflammatory Arthritis Audit \(NEIAA\)](#)

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### Summary

The NEIAA launched in May 2018 and is looking in detail at what happens to patients over 16 years of age in England and Wales with suspected early inflammatory arthritis (EIA) when they are referred to a rheumatology service. Timelines to referral and being seen in a specialist service are collected for all patients with suspected inflammatory arthritis; more detailed information is collected over a 12 month period for all patients with a Rheumatoid Arthritis (RA) pattern of inflammatory arthritis.

Data are collected from both clinicians and patients at three time points: first assessment, 3 month follow up, and 12 month follow up.

The NEIAA patient panel includes 10 patient representatives, two of whom sit on the Project Working Group which steers the direction of the audit. The patient panel meet 2-3 times per year in person, and are consulted every time we do something that will impact patients. We keep in regular contact with our panel, giving them (minimum) quarterly updates. Testimonials from some of the patient panel can be found at: <https://www.myarthritisaudit.org.uk/pages/MYPatientPortal/ppi>.

### Aims and Objectives

People who are suspected to have rheumatoid arthritis or early inflammatory arthritis need to be referred to a rheumatology service and treated as quickly as possible to suppress inflammation and minimise potential damage to joints.

The audit asks patients how inflammatory arthritis affects their day to day function, mobility, sleep, wellbeing and ability to work.

Historically, patient response to audits has been low. We sought to increase the number of Patient Recorded Outcome forms received for this audit, and worked closely with our patient panel in order to do so. Our work, as described below, has been quite ambitious in the amount we are doing to engage patients.

## Outcome

Our patient panel advised the creation of a set of videos to help patients to understand the audit and the importance of data collection. Two videos for patients were commissioned: one featuring the audit project manager and explaining how to use the website, and one featuring the then CEO of NRAS, Ailsa Bosworth, introducing the audit and elaborating on her experience as someone with rheumatoid arthritis. They can be found at [www.myarthritisaudit.org.uk](http://www.myarthritisaudit.org.uk). The guide to the website is the first video to be seen, and once the patient has logged into the homepage, this displays the NRAS video (this is also at the bottom of the not logged in homepage). Patients are guided to this website by our emails that are sent out asking them to fill in the questionnaires. Reminder emails are sent out two weeks later if the forms have not been completed.

Paper versions of the forms were also designed, so patients can return paper versions to their departments if they are not able to access the online forms.

The audit patient website includes patient resources that have been created with the patient panel, including a list of patient resources:

<https://www.myarthritisaudit.org.uk/pagesMYPatientPortal/patres2>

Along with a very simplified patient information page:

<https://www.myarthritisaudit.org.uk/pagesMYPatientPortal/patinf>.

We also have a help line for patients to call, picked up by the audit project manager, to help with navigating the website and answering questions.

All our patient related activity is reviewed and approved by our patient panel, and the CEOs of the patient charities, NRAS and NASS, who sit on our Senior Governance Group.

## Impact

The videos have been very well received, and are the most popular videos on the BSR YouTube channel. We have had feedback that patients are pleased they can watch a video and also speak to the same person on the phone to answer any further questions they may have.

50% of eligible patients returned a questionnaire at the time of diagnosis. This means that we were able to report on patient outcomes for over 3,500 patients in just one year. This is a huge increase from the 557 patients that returned forms in the first year of the 2014-2016 National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

The Patient and Public annual report was written almost entirely by the patient panel. This included a meeting of the patient panel dedicated to the annual report, in which the panel went through the report line by line to make sure the language used was appropriate. They also decided which data went into the patient report. This has been available since 9 October and has been shared with several patient charities to help with dissemination to relevant patients. With such a large number of PROs received, we are hopeful that the impact of this report will be substantial.