

National Early Inflammatory Arthritis Audit (NEIAA)

Thank you for agreeing to take part in the National Early Inflammatory Arthritis Audit. Your support for this project is hugely valuable. The information you provide will help Rheumatology teams improve treatment for others in similar circumstances in the future.

What is the NEIAA?

The National Early Inflammatory Arthritis Audit (NEIAA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government.

The purpose of the NEIAA is to improve the quality of care for patients with rheumatic conditions. The audit assesses care provided to people with a new diagnosis of early inflammatory arthritis, CTD or Systemic Vasculitis. The audit also assesses how these conditions affect day-to-day function, mobility, sleep, wellbeing and ability to work. The NEIAA project team hopes that by asking patients these questions more accurate information will be collected, and patients may feel more able to communicate with their clinicians, families and employers and manage their disease more effectively.

Who will be asked to take part?

All patients aged 16 and over referred to a rheumatology service for the first time with a diagnosis of inflammatory arthritis, CTD or Systemic Vasculitis will be included.

How will information about you be gathered?

Information will be collected from the team you see in the clinic. Members of your rheumatology team will complete questions about your condition. You will be given the option of completing the patient questionnaires at a convenient time for you via an email link to a dedicated patient website. Alternatively, you can complete paper questionnaires and return them to your rheumatology team.

What information will be collected about you?

The audit follows patients through the first 12 months of care in rheumatology outpatient departments. The NEIAA project team know that the early treatment period is essential and sets the foundations for good quality care for years to come.

Information will be collected at the first rheumatology appointment for all patients eligible for recruitment. Further information will be collected 3 months later for those who have a diagnosis of rheumatoid arthritis. The information gathered will answer the following questions:

- How quickly are patients referred to specialist care by GPs and how long does it take to see a specialist in rheumatology?
- What treatment do patients with inflammatory arthritis receive over this first year and is it in line with national (NICE) guidelines?
- How well staffed are rheumatology departments, and do they have access to other specialist services such as physiotherapy, podiatry, psychology, if required?
- Do patients receive timely education about their new diagnosis to help manage their condition well?
- Can patients access advice quickly if required?

What support is available for you to complete the questionnaires?

If you are unclear about how to answer any questions, our patient website (www.myarthritisaudit.org.uk) has information boxes to help you and a page of 'Frequently Asked Questions', as well as a list of resources/charities who may be able to provide assistance. Your Rheumatology team will also be able to help.

What confidential information is collected about you and why?

The confidential information we are collecting is your name, email address, date of birth, NHS number, postcode and gender. The benefit of gathering these personal details is to enable the NEIAA project team to link with other sources of information within the NHS to learn about the impact on patients of inflammatory arthritis and its treatments.

To get this additional information we send your personal details (NHS number, date of birth, postcode) to NHS England/Digital Health and Care Wales. These are the national bodies that collect health care data. They will use your details to find relevant information, which will be returned to the NEIAA project team in an anonymous format. No healthcare information transferred to the NEIAA project team will have personal identifiers and it will not be shared outside the NHS or the NEIAA project team.

What happens to your confidential information?

The NEIAA project team will be collecting this information through a secure website, to which only members of your rheumatology team and the NEIAA project team will have access. The confidential information is stored safely in accordance with NHS standards and regulations and will be held for the duration of the audit, for up to twelve years. The Rheumatology team at King's College London will analyse the information supplied for the audit. In addition, a research database is maintained to help learn from the information collected in NEIAA. Only anonymised patient data are released for the purposes of research.

Before patient data are released:

- All personal identifiers are removed
- All dates are encrypted
- All geographical identifier information is removed
- All hospital identifiers (including NHS numbers) are removed

Sharing data with researchers will always be under relevant legal and information governance regulations. None of your personal information will ever be made public. A flowchart to explain to you how your data will be collected and used is available on the website.

Why have you not been asked for permission to use your information?

The NEIAA has permission to collect personal identifiers from patients without taking explicit (written) consent. This support has been approved by the Secretary of State for Health and Social Care under the Regulations.¹ A summary of the entry for the NEIAA is available on the Health Research Authority's register of approvals (Ref: 18/CAG/0063 & 19 CAG/0059).

What if I do not want to have my information included?

You have the right to have your personal information removed from the audit at any time. Please contact your rheumatology team to let them know that you do not wish to be included. Your rheumatology team will then ensure that your personal details are not entered onto the audit database.

You also have the right to raise concerns or make a complaint through the Information Commissioner's Office by calling 0303 123 1113 or following the link: <https://ico.org.uk/concerns/>

Final comments

Thank you for taking the time to read this leaflet. The NEIAA project team is really grateful for any support you feel able to contribute to this audit. Our hope is that with your help the care available to patients with rheumatic conditions in the future can be improved.

You can find the questionnaire here: www.myarthritisaudit.org.uk/

¹ Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent.