British Society for Rheumatology

National Early Inflammatory Arthritis Audit

Patient and Public Second Annual Report (Data collection: 8 May 2019 – 7 May 2020)

January 2021

HQIP
Healthcare Quality Improvement Partnership

Contents

Key findings

Recruitment

13,578

patients were recruited to the audit in year two

96%

of all NHS rheumatology services in England and Wales participated

Treatment

64%

of patients with a diagnosis of early inflammatory arthritis were prescribed a conventional disease-modifying anti-rheumatic drug (cDMARD) within six weeks of referral

94%

of patients received disease-specific education as reported by clinicians

89%

of patients had a treatment target set and agreed

92%

of patients were given access to a rheumatology specialist advice line

Time to first appointment

3d

47%

of patients were referred within three working days

48%

of patients referred with suspected early inflammatory arthritis were seen within three weeks

16d

16 days

average wait for the first appointment

Reported improvements by 12 months

52%

of people were in disease remission 12 months after diagnosis

49% to 25%

of patients who were depressed or anxious at first appointment and at 12 months

19% to 5%

reports of absenteeism at baseline and at 12 months

45% to 25%

reports of presenteeism at baseline and at 12 months

Background

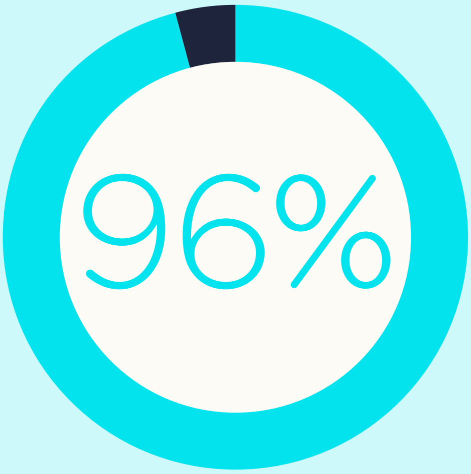
Who is taking part?

The National Early Inflammatory Arthritis Audit (NEIAA) 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 confirmed rheumatoid arthritis (RA) pattern of inflammatory arthritis.

All organisations which provide NHS rheumatology services in England and Wales are required to take part in the audit. This report includes information collected from 8 May 2019 to 7 May 2020. Data collection was non-mandatory from 27 March 2020 due to the COVID-19 pandemic, therefore, data analysed predominantly reflects activity prior to the major impact of COVID-19.

13,578

patients were recruited to the audit in year two



of all NHS rheumatology services in England and Wales participated

Purpose of the audit

People who are suspected to have RA or EIA 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 uses the seven National Institute for Health and Care Excellence (NICE) quality statements to assess the care provided for people with new symptoms of arthritis attending rheumatology services for the first time (Table 1). These quality statements were updated during the second year of the data collection and are now reduced to five statements. This audit still focuses on the previous statements to allow direct comparison with the first-year data.

Table 1. Standards of care

Statement 1	People with suspected persistent synovitis affecting the small joints of the hands or feet, or more than one joint, are referred to a rheumatology service within three working days of presentation.
Statement 2	People with suspected persistent synovitis are assessed in a rheumatology service within three weeks of referral.
Statement 3	People with newly diagnosed rheumatoid arthritis are offered conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within three months of onset of persistent symptoms.
Statement 4	People with rheumatoid arthritis are offered educational and self-management activities within one month of diagnosis.
Statement 5	People who have active rheumatoid arthritis have their C-reactive protein (CRP) and disease activity measured monthly in specialist care until they are in remission or have low disease activity.
Statement 6	People with rheumatoid arthritis and disease flares or possible drug-related side effects receive advice within one working day of contacting the rheumatology service.
Statement 7	People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service.

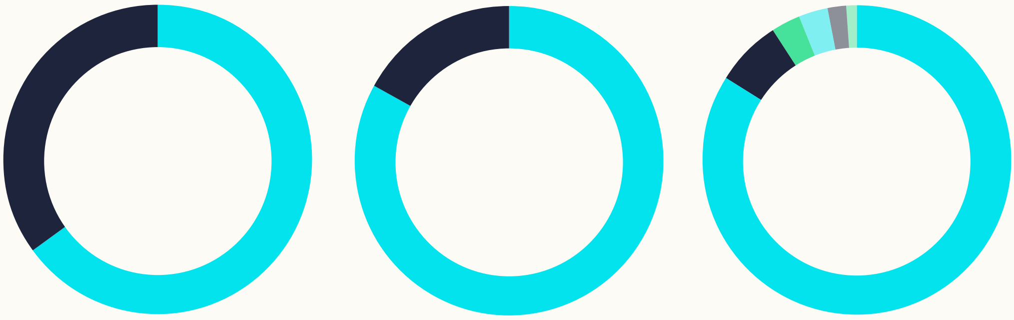
The first annual report focused on the first six quality statements. None of the patients had been enrolled in the audit for 12 months. Findings on QS7 were not included in the first report because data cut-off for analysis was exactly 12 months after the start of data collection. In this report, the performance of rheumatology services is assessed against all seven statements as information on annual reviews is now available.

The audit also assesses how inflammatory arthritis affects people’s day-to-day function, mobility, sleep, mental health, wellbeing and ability to work.

Results

Patient demographics

The audit collected information on diagnosis and patient characteristics, including gender and smoking status, for all patients referred with suspected inflammatory arthritis.



Gender

65%	Female	●
35%	Male	●

Smoking status

83%	Non-smoker	●
17%	Current smoker	●

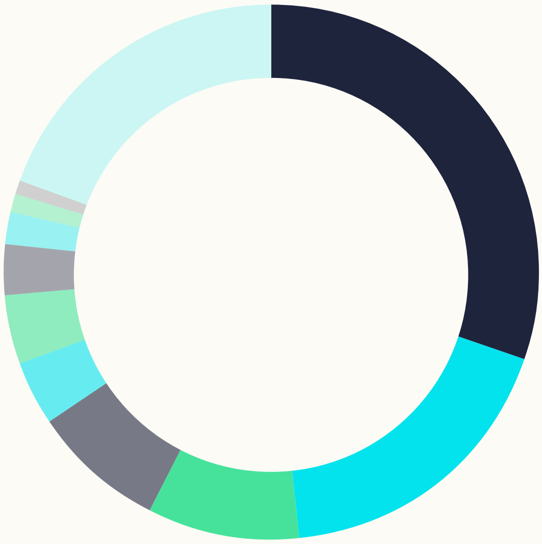
Ethnicity

84%	White	●
7%	Asian/Asian British	●
3%	Black British/African/ Caribbean	●
3%	Other ethnic group	●
2%	Not known	●
1%	Mixed/Multiple ethnic groups	●

Rheumatoid arthritis was the most common diagnosis (30%) and osteoarthritis was the second most common diagnosis (18%).

Diagnosis

30%	Rheumatoid arthritis	●
18%	Osteoarthritis	●
9%	Undifferentiated arthritis	●
8%	Psoriatic arthritis	●
4%	Fibromyalgia	●
4%	Crystal arthritis (gout)	●
3%	Reactive arthritis	●
2%	Axial spondyloarthritis	●
1%	Connective tissue disease	●
1%	Mechanical back pain	●
19%	Other	●



Access to care

NICE quality statement 1 states:
"People with suspected persistent synovitis (inflammation of the joint) affecting the small joints of the hands or feet, or more than one joint, need to be referred to a rheumatology service within three working days of presentation."

When inflammatory arthritis is suspected, early referral is important so that a diagnosis can be made, and treatment offered. The audit found that 47% of patients were referred within three working days of presentation with early inflammatory arthritis symptoms, a 6% improvement on last year's performance. A target of 5% improvement was set in the **audit's quality improvement plan** and, therefore, was achieved.

47%

of patients were referred within three working days

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NICE quality statement 2 states:
"People with suspected persistent synovitis should be assessed in a rheumatology service within three weeks of referral."

Access to specialist care means that treatment can be started early in anyone confirmed to have inflammatory arthritis. This improves pain, function and quality of life, and protects the joints from damage in the early stages of disease. The audit found that 48% of patients referred with suspected early inflammatory arthritis were seen within three weeks, a 10% improvement on last year's performance, therefore meeting the 5% improvement target set out in the **audit's quality improvement plan**. The average time to first specialist assessment was reduced dramatically over 12 months, from 28 days to 16 days. An assessment needs to take place within 15 working days to meet this quality statement. Only 57 (1%) patients waited over six months for assessment, compared to 264 (3%) in year one.

48%

of patients referred with suspected early inflammatory arthritis were seen within three weeks

16d

16 days

average wait for the first appointment, (target is 15 days)

Patients waiting over six month for an appointment reduced by

66%

For quality statements 3 to 7 and for clinician- and patient-reported outcomes, data are presented just for those patients who had a confirmed diagnosis of RA pattern early inflammatory arthritis.

Quality of care

NICE quality statement 3 states:
"People with newly diagnosed rheumatoid arthritis should be offered conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within three months of onset of persistent symptoms."

There is good evidence that the early use of cDMARDs makes the greatest difference to how well patients do in the longer term[1].

Nationally, 64% of patients with a diagnosis of EIA were prescribed a cDMARD within six weeks of referral, a 10% improvement on last year's performance, therefore meeting the 10% improvement target set out in the **audit's quality improvement plan**.

64%

of patients with a diagnosis of early inflammatory arthritis were prescribed a cDMARD within six weeks of referral

Support for self-care

NICE quality statement 4 states:
"People with rheumatoid arthritis should be offered educational and self-management activities within one month of diagnosis."

For this statement, the audit asked both clinicians (members of the rheumatology specialist team) and patients whether disease-specific education had been offered to the patient. This service was offered by telephone, email or an app. The audit found that clinicians reported offering this education to 94% of patients, while 81% of patients reported receiving education by three months. The difference here suggests that sometimes clinicians may not be signposting and/or delivering the education in a clear or detailed way. These findings are in line with the previous year.

94%

of patients were offered disease-specific education (clinician-reported)

81%

of patients received disease-specific education (patient-reported)

Changes made to treatment when required

NICE quality statement 5 states:
"People who have active rheumatoid arthritis have their C-reactive protein (CRP) (a blood test to measure inflammation) and disease activity measured monthly in specialist care until they are in remission or have low disease activity."

The statement was measured by asking "Was a treatment target of low disease activity or remission agreed with the patient?"

'Treat-to-target' is an approach to care that involves a goal for disease control being agreed between patients and clinicians, disease activity being measured monthly and treatment changed if required to improve control of their inflammatory arthritis. Agreement of treatment targets is a good indication to demonstrate how clinicians and patients share decision-making. 'Treat-to-target' in inflammatory arthritis has been shown to result in less joint damage and improved quality of life[2]. The audit found that, nationally, clinicians reported 89% of patients with confirmed EIA had a treatment target agreed, a 5% improvement on the previous year.

89%

of patients had a treatment target set and agreed (clinician-reported)

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Access to specialist support

NICE quality statement 6 states:
"People with rheumatoid arthritis and disease flares or possible drug-related side effects receive advice within one working day of contacting the rheumatology service."

When people experience disease flares or drug-related complications, access to prompt advice from a specialist team helps reduce the problems caused by uncontrolled inflammatory disease and allows rapid change in treatment if needed.

Access to urgent advice via a dedicated advice line is available to a majority of newly diagnosed EIA patients but is not available everywhere. It is possible that Trusts/Health Boards may have developed other methods to provide advice, such as a dedicated email address or app. Clinicians reported that 92% of patients were provided with access to rheumatology specialist advice (e.g. a telephone advice line).

92%

of patients were given access to rheumatology specialist advice

Annual reviews

NICE quality statement 7 states:
"People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service."

Having inflammatory arthritis increases cardiovascular risk, fracture risk and the risk of disability. An annual review provides the opportunity to review and highlight specific risks to the individual.

Clinicians were asked whether they conducted an annual review and whether this included an assessment of bone health, a cardiovascular risk assessment and an assessment of disability. The actual scores for any of these assessments were not recorded. Of those who had returned data on annual review status, 48% had received an annual review, a 5% improvement from year one.

48%

of patients had received an annual review as reported by clinicians

Impact of early inflammatory arthritis

The audit has used some rheumatology 'tools' to show what impact early disease has on patients' lives and how patients respond to treatment during the first 12 months of specialist care.

The audit used the Disease Activity Score (DAS28) to measure disease activity in RA. A score is calculated using information on the number of tender and swollen joints, a score from the patient about their 'global health' and the result of the most recent blood tests measuring inflammation (ESR/CRP). A DAS28 score higher than 5.1 implies severe active disease activity, lower than 3.2 implies low disease activity and lower than 2.6 implies remission.

Table 2. Disease activity measured using DAS28

DAS28 score	Disease activity
< 2.6	Remission
2.6 – 3.2	Low disease activity
3.2 – 5.1	Moderate disease activity
> 5.1	Severe active disease activity

At 12 months,

52%

of patients with early inflammatory arthritis were in remission

Patient-reported outcome (PRO) measures

The audit asked people taking part to complete a questionnaire at the time of their first appointment, at three months and 12 months. The questionnaire asks patients about how their condition is affecting them physically and mentally. The findings below cover data from years one and two combined. Although supply of data from patients has been good, the absolute numbers are relatively low, and this is why data on patient outcomes from both years are included.

PROs were available for 4,996 at baseline, 2,482 at three months and 858 at 12 months. At the first appointment, patients reported a high impact of the disease, with significant levels of functional and work impairment, depression and anxiety. Over the first 12 months of treatment, the audit saw improvement across all the areas assessed on the questionnaires.

PRO data collected:

Musculoskeletal Health Questionnaire (MSK-HQ)

This is a 15-item questionnaire that measures overall health. Scores range from 0 to 56, with higher scores meaning better musculoskeletal health. A clinically meaningful improvement is when the patient's score improves by six points or more.

Musculoskeletal health scores improved from

25.5
at the first appointment

34.8
at three months

37.2
at 12 months

Health Assessment Questionnaire (HAQ)

10 questions have been developed to measure how well people can function and perform day-to-day tasks. Scores range from 0 to 3, with lower scores indicating better ability to perform tasks. A clinically meaningful improvement is when the patient's score reduces by at least 0.22.

The ability to perform tasks improved from

1.1
at the first appointment

0.8
at three months

0.7
at 12 months

Mental Health (PHQ4ADS)

These are the two questionnaires recommended for use in the NHS to identify people who are likely to have significant low mood or anxiety[3,4]. Each measure contains two items, with a score from 0 to 6. The score is combined, and a lower score indicates a lower likelihood that the person completing them has low mood or anxiety. A clinically meaningful improvement is when the patient's score reduces by four points.

49%
of patients with confirmed early inflammatory arthritis met the criteria for a probable low mood or anxiety at diagnosis

This reduced to

30%
of patients at three month follow-up

25%
at the 12-month follow-up

Work status and impact

EIA often affects people of working age. The audit collected information about the effect the disease has on people's working lives using the Work Productivity and Activity Index (WPAI). This measures reduced work attendance (absenteeism), and impact on work performance (presenteeism).

People with higher levels of absenteeism are more likely to lose their job or have to give up work[5]. Not being able to work can have several negative effects including reduced financial security, worsening of physical health, and loss of self-esteem[6]. Information on a patient's ability to work is a crucial measure of the impact of inflammatory arthritis.

Measurement of the impact and offering emotional support as soon as possible is essential to help people remain in the workforce.

In this audit, patients initially reported high levels of absenteeism (19%) and presenteeism (44%). Absenteeism had reduced to 9% at three months and 4% at 12 months and presenteeism had also decreased, to 33% at three months and 27% at 12 months. Overall impairment had reduced from 32.3% to 26.3% at three months and 24.1% at 12 months.

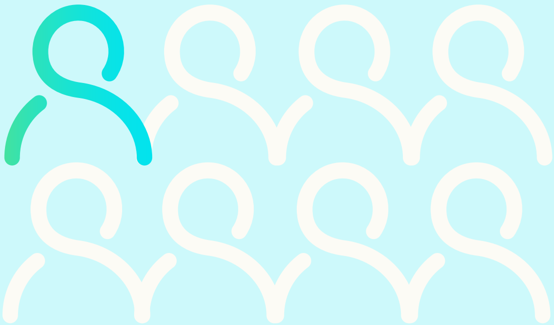
Absenteeism went from	Presenteeism went from	Overall impairment had reduced from
19% at baseline	45% at baseline	32% at baseline
9% at three months	32% at three months	26% at three months
5% at 12 months	25% at 12 months	24% at 12 months

Additional information

Information was available on some additional outcomes using linkages to the national information partners NHS Digital and NHS Wales Informatics Service (NWIS). This was applied for all patients with a confirmed diagnosis of EIA recruited to the audit since May 2018 with a valid NHS number.

Unplanned admissions

Unplanned admissions refer to when a patient is admitted to hospital for any reason other than elective or planned-for care and includes people being admitted via the emergency department. Unplanned admissions are an increasing problem for the NHS and can also be distressing for patients and their families. The audit found that the annual unplanned admission rate was approximately 1 in 8 patients, which is in line with the previous findings of 1 in 7 unplanned hospital admissions within two years of diagnosis. The audit is not able to separate out any admissions directly linked to EIA and its treatment.



Approximately

1 in 8

unplanned hospital admissions

Joint replacements and mortality

It is known from previous research that patients with inflammatory arthritis are more likely to require joint replacement surgery and have a reduced life expectancy than the general population[7]. The audit measured how many patients require joint replacement surgery and mortality rates after a diagnosis of EIA. The audit found that 85 out of 12,185 people recruited to the audit since it started in May 2018 had a joint replacement and 108 deaths occurred. Again, the audit is not able to separate out any joint surgery and deaths directly linked to early inflammatory arthritis and its treatment. The number of joint replacements directly due to early inflammatory arthritis would be expected to be very low in the first few years of a diagnosis, as joint damage usually takes time to accumulate.

Axial spondyloarthritis

Axial spondyloarthritis is a type of inflammatory arthritis mainly affecting the spine. Patients often have other signs such as bowel, eye or skin inflammation and are thus likely to be referred from other specialists as well as from primary care. The audit found that 2% of all patients recruited to the audit were diagnosed with this condition and most of the referrals came from primary care. Compared to patients with RA, patients with axial spondyloarthritis had symptoms for much longer before they were seen in a rheumatology clinic. Over 65% of patients with confirmed axial spondyloarthritis had symptoms for over 12 months. Timely referral and diagnosis are important to reduce the impact of the condition.

Over

65%

of patients with confirmed axial spondyloarthritis had symptoms for over 12 months before having an assessment

What has the audit shown us so far?

The second year of the audit has been successful, with excellent recruitment despite the impact of COVID-19 on data collection. Patients continue to complete more questionnaires than comparable national audits.

The audit has reinforced that inflammatory arthritis has major, diverse effects on patients' mental and physical health. Some of this impact has been shown to reduce over the first 12 months of care. Mortality, joint replacements and unplanned admissions after receiving a diagnosis of inflammatory arthritis have also been reported for the first time. Over time these data will help us understand the factors that can influence these outcomes.

Although the data from year 2 show improvements in the quality of care provided to many patients when compared to year 1, performance against the NICE standards is still below the target of 100%. There continues to be significant variation in performance across England and Wales, with some rheumatology services performing better than others. There needs to be further work to help the team to understand the reasons for these differences.

Where does the audit go from here?

The audit will continue to collect information on early arthritis care across the NHS in England and Wales. The next report will consider the impact of the COVID-19 pandemic on the quality of care provided.

The information collected will help units to improve the quality of care that they deliver to patients with early RA.

To read the full annual report, and to see how your local Trust/Health Board has performed, go to **www.rheumatology.org.uk/neiaa**. You will be able to download the annual report spreadsheet and will find instructions on how to use the spreadsheet on the first page of the document.

Further information

Q&A

My Trust/Health Board has been identified as an outlier – what is this and should I be concerned?
Outlier analysis aims to identify Trusts/Health Boards that have not performed as well as others. An outlier in this audit is a provider (Trust/Health Board) that had long waiting times for patients to be seen after referral. These departments will investigate the reasons for their performance. Outlier status does not necessarily mean that a Trust/Health Board does not provide good quality of care once a patient has been seen for their first appointment.

Please note that the data reported were collected from 8 May 2019 to 7 May 2020 with data collection becoming non-mandatory on 27 March due to the COVID-19 pandemic. Several units have informed us of the actions that they will be implementing to improve their performance.

Who else will you share my information with if I have taken part in the audit, and for what purpose?
Researchers can apply to British Society for Rheumatology (**www.arthritisaudit.org.uk/pages/research**) for access to anonymised information gathered through the audit for research purposes. No identifiable information will be shared.

I have looked at the main report but cannot see all the audit results for my local provider. What is the reason for this?
You can access information for an individual Trust/Health Board via the following link **www.rheumatology.org.uk/neiaa**. If your Trust/Health Board data are not on this spreadsheet this is because your Trust/Health Board recruited very low numbers of patients for the audit. This information is not shown for two reasons:

- the analysis is unreliable as a result of the low numbers;
- it may not be possible to keep information on each patient confidential.

You can find more information about the audit on our patient website:
www.myarthritisaudit.org.uk

Where to go for more information and help

National Rheumatoid Arthritis Society (NRAS)
Freephone 0800 298 7650 to receive information and support if you have rheumatoid arthritis. Support available includes speaking with a trained telephone support volunteer with rheumatoid arthritis at a mutually convenient time about whatever aspect of your rheumatoid arthritis concerns you most. Free information resources are also available. If you have any queries you can email **enquiries@nras.org.uk**. Please check the website for more details: **www.nras.org.uk**

Versus Arthritis
You can read or download information about living with arthritis from this organisation's website, **www.versusarthritis.org**, and read about the latest research.

National Axial Spondyloarthritis Society (NASS)
NASS provides support, advice and information for people with axial spondyloarthritis (axial SpA). Further details can be found at **www.nass.co.uk**

Patient Advice and Liaison Service (PALS)
PALS provides help in many ways, by offering confidential advice, support and information on health-related matters.

Glossary

absenteeism	absence from work
axial spondyloarthritis	an inflammatory disorder which affects the spine and can, in some people, also affect other joints
BSR	British Society for Rheumatology
cDMARD	conventional disease-modifying anti-rheumatic drug
clinician	any healthcare professional seeing you for your arthritis
connective tissue disease	a group of disorders that can impact on many parts of the body as well as causing joint and muscle pain
crystal arthritis	a condition characterised by accumulation of tiny crystals in one or more joints
DAS	Disease Activity Score
fibromyalgia	A condition that is classically characterised by pain, tenderness and fatigue, often affecting the whole body
global health	A patient's self-assessment of how their disease is impacting on them
HQIP	Healthcare Quality Improvement Partnership
NEIAA	National Early Inflammatory Arthritis Audit
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NWIS	NHS Wales Informatics Service
osteoarthritis	a condition characterised by the breakdown and eventual loss of the cartilage within joints
outlier	a Trust/Health Board that has performed significantly below the rest of the country at quality statement 2
presenteeism	reduced productivity at work
PRO	patient-reported outcome
providers	Trusts or Health Boards that provide specialist rheumatology services
psoriatic arthritis	a specific form of inflammatory arthritis that is often linked to the skin condition psoriasis
quality improvement	actions that lead to measurable improvement in healthcare services and the health of patients
reactive arthritis	a specific form of inflammatory arthritis that is classically triggered by an infection; the inflammation also affects the joints, eyes, skin and urinary tract
remission	a period in the course of a disease when the inflammation is controlled
rheumatoid arthritis	a specific inflammatory disorder that causes pain, swelling and stiffness in the joints, particularly the hands, feet and wrists
synovitis	inflammation of the lining of a joint
undifferentiated arthritis	an inflammatory arthritis for which no definite diagnosis can yet be made, usually because the disease is in an early stage and/or results of tests are not yet available

Appendix 1

Patient Panel

Amlani-Hatcher Paul (Chair)
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Acknowledgements

This report was prepared by members of the National Early Inflammatory Arthritis Audit (NEIAA) operations team and the Patient Panel, with data provided by patients and staff within the NHS or private hospitals. The continued success of this national clinical audit is due to the hard work and commitment of the rheumatology clinical community. British Society for Rheumatology (BSR) is very grateful to all the clinical and administrative staff and patients who support and contribute to the NEIAA.

HQIP

The NEIAA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP aims to promote improvement in patient outcomes, and to increase the impact that clinical audit, outcome programmes and registries have on healthcare quality in England and Wales. HQIP currently oversees over 40 projects covering the care provided to people with a wide range of medical, surgical and mental health conditions. Funding for the NEIAA and for most work that The HQIP does is by NHS England and the Welsh Government.

British Society for Rheumatology (BSR)

BSR exists to promote excellence in the treatment of people with arthritis and musculoskeletal conditions, and to support those delivering health services. BSR is responsible for engaging with Trusts and Health Boards, sharing best practice, managing communication and holds the contract to run this audit.

Net Solving

Net Solving created the online data collection platform. It has 15 years of experience working with clinical data collection web tools in the UK and worldwide. It is committed to its work with BSR on the NEIAA project.

King's College London

The Centre for Rheumatic Diseases at King's College London has analysed all the information provided for the audit and produced the results shown in this report.

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