



A patient and public guide **National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis**

2nd Annual Report 2016

(Data collection: 1 February 2015 – 29 January 2016)



HQIP

Healthcare Quality
Improvement Partnership



Contents

Background

Who took part?	3
Purpose of the audit	4

Results

Access to care	6
Quality of care.....	8
Support for self-care.....	11
Impact of early arthritis.....	13
– Severity of early disease - Disease Activity Score (DAS-28)	
– Effect on patient’s life - Rheumatoid Arthritis Impact of Disease (RAID) score	
Experience of care.....	15
– Patient reported experience measures	
– Work	
What has the audit shown us so far?	17
Where does the audit go from here?	18

Further Information

Q&A	19
Where to go for more information and help	20
Glossary	21
Acknowledgements.....	22

Background

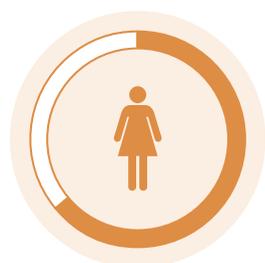
Who took part?

The second national clinical audit for rheumatoid and early inflammatory arthritis looks in detail at what happens to patients over 16 years of age in England and Wales with suspected rheumatoid or other types of early inflammatory arthritis within the crucial first 3 months of referral to a specialist. In this report, we present the audit findings from year 2 and comment on changes since year 1.

All organisations (both public and private) which provide NHS rheumatology services in England and Wales were eligible to take part in this audit. Northern Ireland and Scotland were invited to participate but chose not to at this stage. This report includes data collected from 1 February 2015 to 29 January 2016. This includes a recruitment period of 9 months, followed by 3 months of follow-up on these patients. In total, 11,356 patients were recruited in the two year data collection period.

5,002

patients were recruited to the audit in year 2



64%
were female



70%
were aged 16-65



91%
of all NHS rheumatology services in England and Wales took part

Purpose of the audit

The audit aims to assess the early management of patients referred to rheumatology providers with suspected inflammatory arthritis and to enable patients to provide feedback on the services provided to them and on the impact of their arthritis on their lives.

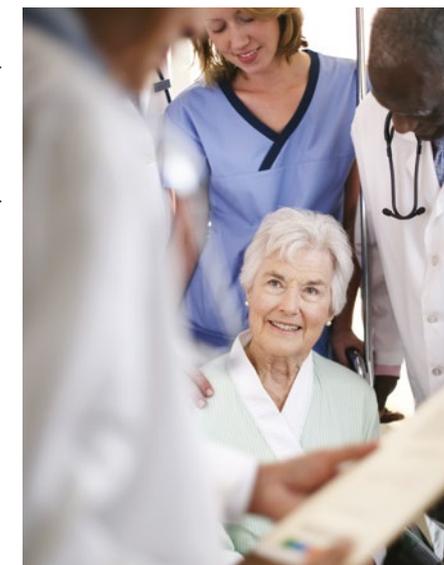
The audit gives detailed information on the following:

- » Access to care - It shows how quickly patients are referred to specialist care by their GP and how long they wait for their first appointment with their rheumatology team.
- » Quality of treatment and care received by patients from their rheumatology team in the first 3 months - This includes details about medications used, access to services, department staffing levels and support for self-care.
- » Early impact of arthritis on a patient's life - This includes their ability to work, how patients feel about care received and their early response to treatment.

These data continue to provide valuable insight into areas that have previously had very little national information.

The audit measured the speed of access to care and quality of care within the first 3 months of referral against national standards for the management of rheumatoid arthritis in adults. These standards were developed by the National Institute for Health and Care Excellence (NICE).

Before you read the results section and particularly if you have been newly diagnosed with inflammatory arthritis, you may find it helpful to see what levels of care you should expect from your GP and rheumatology services. The standards are set out overleaf.



NICE Quality Standards describe high priority areas for quality improvement in the diagnosis and management of rheumatoid arthritis in adults

Standard 1

People with suspected persistent synovitis affecting the small joints of the hands or feet, or more than one joint, should be referred to a rheumatology service within 3 working days of presentation.

Standard 2

People with suspected persistent synovitis should be assessed in a rheumatology service within 3 weeks of referral.

Standard 3

People with newly diagnosed rheumatoid arthritis should be offered short-term glucocorticoids and a combination of disease-modifying anti-rheumatic drugs by a rheumatology service within 6 weeks of referral.

Standard 4

People with rheumatoid arthritis should be offered educational and self-management activities within 1 month of diagnosis.

Standard 5

People who have active rheumatoid arthritis should be offered monthly treatment escalation until the disease is controlled to an agreed low disease activity target.

Standard 6

People with rheumatoid arthritis and disease flares or possible drug related side effects should receive advice within 1 working day of contacting the rheumatology service.

Standard 7

People with rheumatoid arthritis should receive a comprehensive annual review that is coordinated by the rheumatology service.

Results

The results of the audit were provided to all participating providers and commissioners. This helps them look at areas where their care is good and where service improvement is necessary. A number of providers made changes in the way care was provided, based on the findings of the audit in year 1, but it is too early to expect to see the impact of many of these recent changes.

If you want to see how your local provider has performed, you can access the main report here:

http://rheumatology.org.uk/resources/audits/national_ra_audit/annual_report.aspx



20%

of patients were referred to a specialist within 3 working days of seeing their GP for the 1st time with swollen joints

Access to care

NICE standard 1 states that:



People with suspected persistent synovitis (swelling) affecting the small joints of the hands or feet, or more than one joint should be referred to a rheumatology service within 3 working days of presentation to their GP. ”

Time taken to gain a referral from GP

People have often waited a while before making an appointment to see their GP as inflammatory arthritis often develops slowly. When rheumatoid arthritis (RA) is suspected, early referral is important so that a diagnosis can be made and treatment and support offered.

No clinically meaningful difference in referral time or on the percentage achieving this target was observed between year 1 and 2. Small differences were apparent and largely reflect a subtle change in reporting - in year 1, the audit reported delay in 'days', whilst year 2 reports 'working days'. The average wait did however fall slightly from 23 to 20 working days nationally, although more than 1/4 of patients waited over 70 days for their referral. This suggests that rheumatology health professionals need to continue to work closely with GPs to raise awareness of the early signs and symptoms of inflammatory arthritis and prioritise early referral to a specialist.

Time taken to see a specialist after referral

Access to specialist care means that treatment can be started early. This improves pain, function and quality of life and protects the joints from damage in the early stages of disease. There has been no improvement in the time taken to access rheumatology services from year 1 to year 2.

The average waiting time nationally remained the same at 4 weeks and three-quarters of patients were seen within 7 weeks. These figures represent an ongoing significant delay for most patients in gaining a specialist assessment.

The audit recorded a number of factors that help us understand a service's ability to offer an appointment within 3 weeks. These include staffing levels, whether clinics were provided specifically for early arthritis, whether referral letters provided enough information to indicate that inflammatory arthritis was suspected and whether the first appointment offered was cancelled or rearranged by patients.

NICE standard 2 states that:

“People with suspected persistent synovitis (swelling) should be assessed in a rheumatology service within 3 weeks of referral.”

The audit results from the first year have helped us understand that higher numbers of consultants in a provider and the availability of a clinic specifically for early arthritis were factors which are associated with shorter waiting times to first appointment.

This year, there has been a further reduction in the average ratio of consultants to the population (from an average of 1.1 consultants per 100,000 population to 0.86). Even at the highest staffing levels, consultant numbers fall short of the recommendation by the Royal College of Physicians of one rheumatologist per 86,000 people in the local population.

We are however aware that a number of providers have used the audit data to make a case to increase the number of consultants available.



37% of patients were seen in a rheumatology department within 3 weeks of referral

Quality of care

NICE standard 3 states that:

“People with newly diagnosed rheumatoid arthritis should be offered short-term glucocorticoids (steroids) and a combination of disease-modifying anti-rheumatic drugs by a rheumatology service within 6 weeks of referral.”

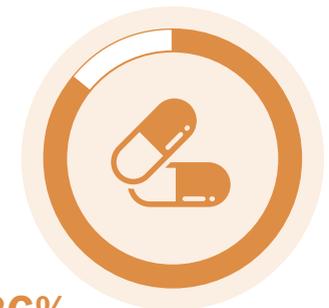


Treatment and services for rheumatoid arthritis

Audit data in relation to this standard is presented just for those patients who had a confirmed diagnosis of RA (3,185 patients/ 64% of patients recruited to the audit). This is because there is good evidence that the early use of steroids and/or disease-modifying treatment in RA makes the greatest difference to how well patients do in the longer term.



68% of patients started DMARDs within 6 weeks



86% of patients received steroid therapy to alleviate their early symptoms



This represents an impressive 15% improvement in patients starting DMARDs early from year 1, although there is still room for improvement. In addition, there was a 4% increase in patients receiving steroid therapy.

Whilst the standard refers to offering treatments, the audit has reported on patients starting treatment. How early treatment is started may be affected by a number of factors including access to investigations such as blood tests, x-rays and ultrasound at the first visit and the availability of follow up appointments. Patients also need time to weigh up the pros and cons of treatments when these

have possible side effects. This often requires a separate appointment with a specialist nurse. In a shared decision making approach, patients may decide against treatment for a variety of reasons and health professionals may need to delay treatment for medical reasons.

Disease modifying treatments may also be started one at a time rather than in combination from the outset and some treatments, such as methotrexate, need to be gradually increased until the arthritis is well controlled. The audit also found that higher numbers of specialist nurses were linked to patients starting DMARDs within 6 weeks.

NICE standard 5 states that:



People who have active rheumatoid arthritis should be offered monthly treatment escalation until the disease is controlled to an agreed low disease activity target. ”

Treating to target is an approach which means that patients should expect to have their disease activity measured regularly, agree a target with their health professional and escalate treatment if required to improve control of their arthritis. This standard is difficult to measure within the time period and structure of the audit. The treatment target set may have been to achieve low disease activity, remission or improved function. What the audit does tell us in relationship to this is that:

Higher numbers of specialist nurses were also linked to whether patients achieved agreed treatment targets at follow up.

The reasons for this cannot be identified from the audit but disease-modifying drugs are known to be slow acting, often need to be increased gradually and may take up to 3-6 months to be effective. This has only improved a little from the first year (49%) and remains a concern because early control of inflammation is known to lead to better outcomes for patients with RA.



92%
of patients agreed a treatment target with their health professional

Whilst performance against this standard remains high, this information was based upon information provided by health professionals in the audit and the extent to which patients felt they had agreed a target was not assessed.

It may not always be possible to seek agreement on treatment targets with patients due to time pressures in clinic or consultation styles. Only 52% of patients nationally achieved their treatment target within the first 3 months of specialist care.



Support for self-care

NICE standard 4 states that:

“ Patients with rheumatoid arthritis should be offered educational and self-management activities within 1 month of diagnosis. ”



92% of patients had access to urgent advice within 1 working day

This result was based upon information provided by health professionals to the audit and represents an improvement of 8% since year 1. Structured patient education and self-management services might include referral to NRAS, provision of paper-based resources, one-to-one sessions with a specialist nurse or attendance at a formal education group. A key factor that may affect the provision of education is specialist nursing staffing levels as patient education is usually a key component of their role.

NICE standard 6 states that:

“ People with rheumatoid arthritis and disease flares or possible drug related side effects should receive advice within 1 working day of contacting the rheumatology service. ”

Nationally there has been a reported decrease of 4% in services meeting this standard since last year. Reasons for this are unclear but urgent advice is usually provided through advice lines staffed by specialist nurses and so achievement of this standard may relate to the availability of specialist nurses.



67% of patients were offered structured patient education and self-management service within 1 month of diagnosis

NICE standard 7 states that:

“ People with rheumatoid arthritis should have a comprehensive annual review that is coordinated by the rheumatology service. ”



82% of providers reported that they provided a comprehensive annual review process for people with rheumatoid arthritis



We cannot compare this result with year 1 as we are now coding this information differently and believe this to be more accurate. Within the 3 month audit period, we did not assess the extent or quality of annual review. Annual review is considered important to ensure that all aspects of the disease are under control. It provides a regular opportunity to assess whether the patient needs any further support to enable them to maximise their quality of life.

We also continued to collect information through the organisational forms about staffing levels and patient services available at each individual trust. Multi-disciplinary team working is essential to improving mobility, function and pain in inflammatory arthritis. Overall 72% of providers reported access to specialist physiotherapy, 76% to specialist occupational therapy and 51% to specialist podiatry services.

There was variation in access to services across England and Wales and provision of specialist foot care (podiatry) was particularly low and patchy indicating room for improvement. This represents little change in access to the multi-disciplinary team from last year.

Impact of early arthritis

The audit has used some rheumatology 'tools' to show us what impact early disease has on patients' lives and their response to treatment during these first 3 months of specialist care. Information was also gathered from patients on their ability to work.

Severity of early disease – Disease Activity Score (DAS-28)

This tool measures disease activity in rheumatoid arthritis. It is calculated using several tests including the number of tender and swollen joints, an assessment of how well the patient feels their condition is and the results of their most recent blood test. A DAS-28 greater than 5.1 implies active disease, less than 3.2 implies low disease activity and less than 2.6 implies remission.

You can find more information on the DAS-28 here:

<http://www.nras.org.uk/the-das28-score>

Health professionals were asked to report the score at the time the patient was first seen and at follow up appointments. Levels of disease activity at baseline were similar to those recorded in year 1, with approximately 90% of patients presenting with severe or moderate disease activity.

The audit found that in the first three months of care, 38% of patients achieved a reduction in DAS by 1.2. A reduction in DAS by 1.2 or more is thought to represent a noticeable improvement in disease activity for the individual.

Effect on patient's life – Rheumatoid Arthritis Impact of Disease (RAID) score

The RAID score shows how rheumatoid and other inflammatory arthritis affects a patient's daily life. Patients were asked to rate their pain; function; fatigue; sleep; physical and emotional well-being and coping. Each category is marked from 0 (best) to 10 (worst). Patients were asked to complete this at their first appointment and then again, three months later. An overall score was calculated from this information by health professionals. Baseline and follow-up RAID scores were available for 43% of patients with RA. This represents a significant improvement (more than 100%) in capturing this information on year 1.

The average RAID score at presentation was 6.1, demonstrating a major impact of early inflammatory arthritis on daily life. The audit found that the average improvement in the overall RAID score was 3 points from the first appointment. This is thought to represent a significant improvement for patients. A 50% improvement in RAID score is also thought to be important but only a fifth of patients achieved this within the 3 months. Whilst this is disappointing, it is worth emphasising that DMARDs often need to be increased slowly up to a target dose and can take up to 3 months to take effect. The effects of steroids given at first appointments may also have worn off by the time of 3 month review. It is also worth noting that RAID scores at follow up were only completed by half of the patients with RA.



Experience of care

Patient Reported Experience Measures (PREM)

Patients completed a confidential questionnaire about their experience of specialist care as part of their 3 month follow up form. The questionnaire was developed by patient groups together with the Commissioning for Quality in Rheumatoid Arthritis group (CQRA).

This type of form and others like it are known as PREMs (Patient Reported Experience Measures).

Although many detailed questions were asked to enable providers to gain a full understanding of patient experience, we again chose the same summary question to report on in this report:

‘Overall in the past 3 months I have had a good experience of care for my arthritis?’

The number of patients who reported a good experience of care has increased greatly from 78% in year 1. This is encouraging and suggests that most patients were happy with the care that they received although it is based upon feedback from just 43% of patients. This is an improvement from last year with 69% more patients answering this question. This may be because services have tried to make follow-up forms routinely available and taken steps to improve their return anonymously through audit departments.

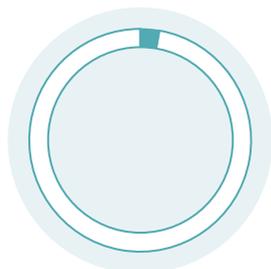
Rheumatology services are being asked to look closely at the feedback patients have provided and in particular to focus on how they can improve experience of care if they have received poor feedback.

940

patients who returned their forms were:



95%
agreed



3%
neither agreed
nor disagreed



1%
disagreed



Work

Early inflammatory arthritis most often presents in people of working age - over 70% of people recruited to this national audit were under 66 years of age. The audit collected information about the affect the disease was having (if any) on peoples' working lives at this time.

The audit shows us 14% needed frequent time off work or were not working because of RA. A further 17% have occasionally needed time off. These results show a small increase from year 1, although the reasons for this are unclear.

The audit also asked patients if they recalled ever being asked by their rheumatology team about their work. 66% of those who did said that they had been asked about their work which is a significant improvement from year (42%). 18% said it had not been discussed while the rest could not recall or did not answer the question.

Whilst the sample size remained limited, these data show that many people with arthritis struggled to work in the early stages of receiving treatment. This suggests that asking patients about impact of RA on work is vital in the first 3 months in order to provide and signpost support. This is important to help prevent problems with work turning into long term difficulties or job loss. This aspect of the 1st annual report has been one of the most widely used by participants and other organisations and we believe that this focus has driven improvements in patient consultations. To further improve this area, the BSR is providing training courses in 4 regions in 2016.

What has the audit shown us so far?

The audit continues to show us that most people with early inflammatory arthritis wait too long from when their symptoms start until they start disease-modifying treatment. There are often delays in referral from GPs and then further delays following referral.

During this second year, we have seen more patients starting DMARDS within 6 weeks, improved patient satisfaction and shown the impact of specialist nursing numbers on starting and escalating treatment. There were also improvements in recruitment and information levels to the audit, in particular the volume of patient data collection and follow up forms.

Here is a summary of what the audit has shown us so far (Year 1 and 2):

- » There is a need to improve early recognition by GPs of possible inflammatory arthritis, and ensure prompt referral for people who are affected. Public awareness of inflammatory arthritis needs to be raised alongside the importance of seeing a GP quickly if symptoms develop.
- » Appointments need to be available for patients to be seen within 3 weeks in the specialist setting. The audit found in the first year that adequate consultant numbers, correct information in referral letters and the use of early arthritis clinics seemed to help patients to be seen more quickly. Appointments also need to be available to follow patients up regularly to provide effective treatment and care.

» Staffing levels impact on care and need to be looked at carefully. The audit shows us that the availability of consultants can affect waiting time to first appointment and that the availability of specialist nurses affect how quickly patients start DMARDS.

» We need to continue to explore how well patients with RA in England and Wales are treated and supported once their diagnosis is made. This includes not only timely access to treatment but also access to structured patient education and support for their work. The audit has shown some improvement in these areas particularly around starting DMARDS and health professionals asking about work in consultations.

» There is a need to improve data collection. Better NHS systems for collecting, coding and using information are needed in conjunction with reviewing the level of support provided by audit departments. Many of the providers that did not take part in the audit felt unable to do so due to lack of resource.

Where does the audit go from here?

Whilst the current audit has drawn to a close, planning for commissioning the next stage of the audit will commence shortly. This gives an opportunity for everyone involved (providers, commissioners and the broader NHS) to look at ways to improve services based on the recommendations.

We would welcome feedback on the audit findings and report, which should be sent to Rose David at the BSR (rdavid@rheumatology.org.uk)

Each rheumatology provider receives the annual report, which compares their performance against that of other providers in their region and across England and Wales. This helps health care professionals, managers and commissioners to reflect upon their performance to date against the standards and develop service improvement plans where needed. Some providers performed much better than others which has also been a key finding of the audit and those that are doing well are encouraged to share information on what works well for them to help other services.



Further information

Q&A

I find some of the rheumatology terms confusing particularly when I have looked at the main report. Is there a list that can help explain these to me?

This patient and public report has been produced to summarise the findings of the main report in a more accessible and easy to read format. There are also explanations and links to various rheumatology tools, forms and questionnaires throughout the document that should help develop your understanding of key terms and concepts. There is also a glossary on page 21.

My trust has been identified as an outlier - what is this and should I be concerned?

Outlier analysis aims to identify 'unusual differences' in data from 'normal variations'. An outlier in this audit is a provider that has shown unusually long waiting times for patients to be seen after referral. These departments will be investigating why this is and there are a lot of potential reasons for this. Being an 'outlier' does not necessarily mean that this department does not provide good quality of care once a patient has been seen for their first appointment.

If you have a concern about your hospital's performance, you should talk about it with your rheumatology team.

I have looked at the main report but cannot see all the audit results for my local provider. Why is this?

If a provider has been identified as having recruited very low numbers of patients, the results may not be shown for two reasons. Firstly, as the analysis is unreliable as a result and secondly because confidentiality of patient data may be compromised.

Who else will you share my information with, if I have taken part in the audit and for what purpose?

Information gathered from this audit is used to help improve patient care in England and Wales. Researchers can apply to the British Society of Rheumatology for access to anonymised information gathered through the audit for research purposes.

I am interested in this audit as I have been newly diagnosed with rheumatoid arthritis are there any other publications that can help me?

There are many organisations and publications that can help educate and support you in addition to the care you are receiving from your rheumatology team. These are listed on page 22.

If you have specific questions or concerns about your own treatment or care, you should contact your rheumatology department.

Where to go to for more information and help

National Rheumatoid Arthritis Society (NRAS)

Freephone 0800 298 7650 to receive information and support if you have RA, including the option to speak with a trained telephone support volunteer with RA at a mutually convenient time about whatever aspect of your RA concerns you most. Look at the website for more details: www.nras.org.uk

Arthritis Care

Freephone 0808 800 4050 to receive information and support if you have any form of arthritis. The website - www.arthritiscare.org.uk - includes a Discussion Forum.

Arthritis Research UK

You can read or download lots of high quality information about living with arthritis from the website - www.arthritisresearchuk.org – and read about the latest research.

National Ankylosing Spondylitis Society (NASS)

NASS provides support, advice and information for people with AS. Further details can be found here: <http://nass.co.uk>

Patient Advice and Liaison Services (PALS)

PALS provide help in many ways by offering confidential advice, support and information on health-related matters. For example, it can:

- » help you with health-related questions
- » help resolve concerns or problems when you're using the NHS
- » tell you how to get more involved in your own healthcare

Glossary

Acronyms

AS

Ankylosing Spondylitis

BSR

British Society for Rheumatology

CQRA

Commissioning for Quality in Rheumatoid Arthritis

DAS

Disease Activity Score

DMARDs

Disease Modifying Anti Rheumatic Drugs

HQIP

Healthcare Quality Improvement Partnership

NICE

National Institute for Health and Care Excellence

NRAS

National Rheumatoid Arthritis Society

PREM

Patient Reported Experience Measure

PROM

Patient Reported Outcome Measure

RA

Rheumatoid Arthritis

RAID

Rheumatoid Arthritis Impact of Disease

REMISSION

A period in the course of a disease when symptoms become less severe

Acknowledgements

HQIP

The audit for rheumatoid and early inflammatory arthritis is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCA Programme and runs more than 30 audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government. Some individual audits are also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands.

Northgate Public Services

Northgate Public Services is a software and outsourcing business. Northgate is responsible for the IT audit tool, the helpdesk and overall contract management. The IT audit tool is hosted within Northgate Public Services' secure data centre and is made available to clinicians in NHS Rheumatology units via a secure browser (over the N3 network).

British Society for Rheumatology

The British Society for Rheumatology (BSR) exists to promote excellence in the treatment of people with arthritis and musculoskeletal conditions and to support those delivering it. The BSR is responsible for engaging with trusts, sharing best practice, managing communication and setting the parameters of the analysis.

MRC Lifecourse Epidemiology Unit, University of Southampton

The Medical Research Council (MRC) Lifecourse Epidemiology Unit at the University of Southampton is a major MRC University-Unit Partnership. It employs around 90 clinical, epidemiological and statistical researchers addressing the cause and prevention of musculoskeletal and metabolic disorders throughout the lifecourse. The unit is responsible for the statistical analysis of the audit data.



The British Society for Rheumatology

Bride House, 18–20 Bride Lane
London EC4Y 8EE

Tel: +44 (0)20 7842 0900

Fax: +44 (0)20 7842 0901

bsr@rheumatology.org.uk

www.rheumatology.org.uk

VAT No: 404 5637 66

Company Reg No: 3470316

Charity No: 1067124