

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

1st Annual Report 2015

(Data collection: 1 February 2014 – 30 April 2015)



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Background

Who is taking part?

The first 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.

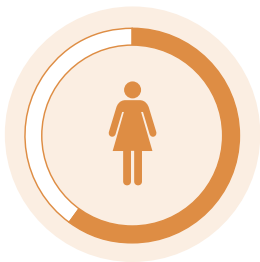
All organisations (both public and private) which provide NHS rheumatology services in England and Wales were eligible to take part in this audit. Organisations are required to report their participation in their Quality Accounts. Northern Ireland and Scotland were invited to participate but chose not to at this stage. This report includes data from 1 February 2014 to 30 April 2015.

In the participating trusts and health boards, we looked at the size of the local population and how many patients we would expect them to have recruited to the audit. At national level, the audit team estimated that approximately half of expected patients had been recruited to take part in the first year of the audit.

It has also been possible to identify trusts who had recruited fewer patients than expected for the size of their local population.

6,354

patients were recruited to the audit



66%
were female



70%
were aged 16-65



97%
of all NHS rheumatology services in England and Wales participated

Purpose of the audit

People who have rheumatoid arthritis (RA) or early inflammatory arthritis need to be referred to specialist care and treated as quickly as possible to suppress inflammation and minimise potential damage to joints.

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.

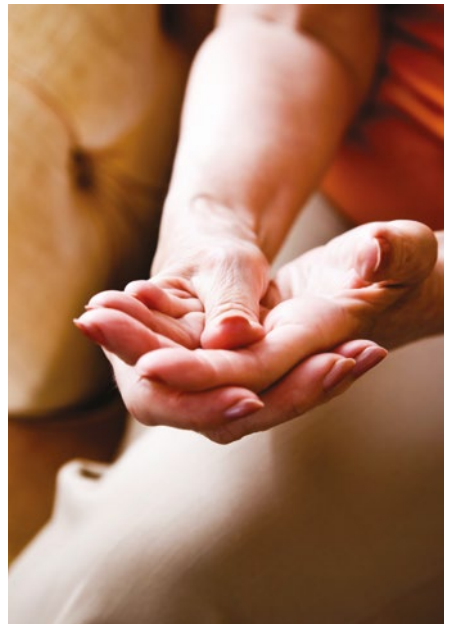
- » Quality of treatment and care received by patients from their rheumatology team in these first 3 months. This includes details about medications used, access to services and support for self-care.

- » The early impact of arthritis on a patient's life including their ability to work, how patients feel about care received and early response to treatment. These data 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.

[See page 6](#)



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 have a comprehensive annual review that is coordinated by the rheumatology service.

Results

The results of the audit were provided to all participating trusts and commissioners. This helps them look at areas where their care is good and where service improvement is necessary.

The findings of the audit are publicly available. If you want to see how your local trust is performing so far, you can access the main report here:
http://rheumatology.org.uk/resources/audits/national_ra_audit/default.aspx



17%

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 can develop slowly. When rheumatoid arthritis is suspected, early referral is important so that a diagnosis can be made and treatment and support offered.

The average wait was 34 days nationally and one quarter of patients waited for more than 3 months for referral from primary care. This suggests that rheumatology health professionals need 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.

The average waiting time nationally was 4 weeks and three-quarters of patients were seen within 7 weeks. This represents a significant delay for most patients in gaining a specialist assessment.



38%

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

The audit recorded a number of factors that could impact on a service's ability to offer an appointment within 3 weeks. These include staffing levels within the trust, whether clinics are provided specifically for early arthritis, whether referral letters provide enough information to indicate that inflammatory arthritis is suspected and whether the first appointment offered is cancelled or rearranged.

The audit results suggest that higher numbers of consultants in a trust and the availability of a clinic specifically for early arthritis are factors which are associated with shorter waiting times to first appointment.

Even at the highest 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.

NICE standard 2 states that:



People with suspected persistent synovitis (swelling) should be assessed in a rheumatology service 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. ”



53%

of patients started DMARDs within 6 weeks

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 (3,258 patients). 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.

You will note that 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. Over the 3 month time period of the audit, a total of 53% of patients went on to start combined disease modifying medication and 82% received steroid therapy to alleviate their early symptoms.

Treating to target is an approach which means that patients should expect to have



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. ””

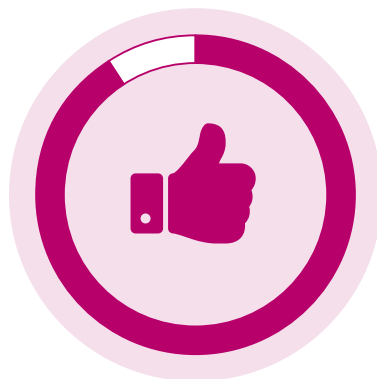
their disease activity measured regularly, agree a target with their health professional and escalate treatment if required to improve control of their arthritis.

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.

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.

Reasons for failing to seek agreement on treatment targets with patients are not known but may relate to time pressures in clinic or consultation styles. Only about 27% of patients nationally achieved their treatment target within the first 3 months of specialist care.

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 result is a concern however because early control of inflammation is known to lead to better outcomes for patients with RA.



91%
of patients agreed a treatment target with their health professional

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. ”

This result was based upon information provided by health professionals in the audit. 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. ”





59%

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



96%

of patients had access to urgent advice within 1 working day



100%

of trusts reported that they provided a comprehensive annual review process for people with rheumatoid arthritis

This is usually provided in the form of a rheumatology advice line which is normally staffed by specialist nurses who provide urgent advice. The information provided by health professionals suggests that this is a key component of care across England and Wales that is well established.

NICE standard 7 states that:



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

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 collected 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 75% of trusts report access to specialist physiotherapy, 77% to specialist occupational therapy and 55% to specialist podiatry services.

There was variation in access to services across England and Wales and provision of specialist foot care (podiatry) is particularly low and patchy indicating room for improvement.

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 you have, an assessment of how well you feel your condition is and the results of your 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. The audit found that in the first three months of care, 62% 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 is calculated from this information by health professionals.

The audit found that the average improvement in the overall RAID score was by 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 highlighting again that disease-modifying drugs 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 (PREMs)

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 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).

You can access the form here:

http://rheumatology.org.uk/includes/documents/cm_docs/2014/i/inflammatory_arthritis_audit_patient_follow_up_form.pdf



Although many detailed questions were asked to enable trusts to gain a full understanding of patient experience, we chose one summary question to report on in this first report:

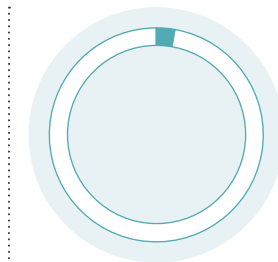
'Overall in the past 3 months I have had a good experience of care for my arthritis?'

557

patients who returned their forms were:



78%
agreed



3%
neither agreed
nor disagreed



1%
disagreed



Whilst it is encouraging to see patients reported high levels of satisfaction overall early in their care, not all patients completed this questionnaire so these findings need to be treated with caution.

Only 41% of patients recruited to the audit completed their 3 month follow up form which included this questionnaire. Of those who did, 17%¹ of patients left this particular question unanswered although they filled in other parts of the questionnaire. This may be for a number of reasons, including the fact that it is a long form.

Patients may not feel confident that their feedback would be confidential, or may simply feel they had not had enough time to assess the quality of care in the 3 month time frame. The audit team are keen to work at ways of encouraging patients to provide this important feedback.

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.

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 reported that one in eight patients (12%) need frequent time off work or are not working because of their arthritis. A further 16% have occasionally needed time off.

The audit also asked patients if they recalled ever being asked by their rheumatology team about their work. Only a small number of patients completed this questionnaire but 42% of those who did said that they had been asked about their work, 19% said it had not been discussed while the rest did not answer the question.

Again, while recognising the data was collected from the patient follow up form and the numbers of responses were low, this highlights that many people with arthritis struggle 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.

¹ Percentages were rounded to the nearest whole number and so the overall total does not equate to 100%.

What has the audit shown us so far?

The audit shows 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. Rheumatology services, GPs and commissioners need to work together to:

- » Improve early recognition of possible inflammatory arthritis, and prompt referral for people who are affected. We also need to increase public awareness of inflammatory arthritis and of the need to see a GP quickly if affected.
- » Ensure that appointments are available for patients to be seen within 3 weeks in the specialist setting. The audit found that adequate consultant numbers and the use of early arthritis clinics seem to help patients to be seen more quickly but appointments also need to be available to follow patients up regularly to provide effective treatment and care.
- » Find ways to improve how well patients with RA in England and Wales are treated and supported once their diagnosis is made. This includes improving how quickly they access treatment, education and support for their work. Timely appointments need to be available to allow patients to be reviewed regularly to provide effective treatment and care.
- » Provide feedback on the audit in order to monitor the improvements in quality of care.

Each rheumatology service received the annual report, which compares their performance against that of other trusts in their region and across England and Wales.

This will enable health care professionals, managers and commissioners to reflect upon performance against key standards and develop service improvement plans where needed. Some trusts do much better than others and may be able to share information on what works well for them to help other services.



Where does the audit go from here?

- » The analysis for patients recruited in the 2nd year of the audit will start shortly.
- » Some trusts recruited fewer patients than expected and it has been difficult to capture some follow up information, particularly from patients who have to return these forms independently. These aspects of the audit areas are being addressed with targeted audit support being given to low recruiting trusts.
- » This audit closes on 31 April 2016. Following a pause to review data collection and processes, the next phase of the audit will be recommissioned for a recommended 3-year period in 2016.

Feedback would also be welcomed from you and you can give this on this form:

http://www.rheumatology.org.uk/resources/audits/national_ra_audit/default.aspx



Further information

Questions and answers

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 22.

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 trust 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 trust. Why is this?

If a trust 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 21.

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.

Patient Advice and Liaison Services (PALS)

<http://www.nhs.uk/chq/Pages/1082.aspx?CategoryID=68&SubCategoryID=153>

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

BSR

British Society for Rheumatology

CQRA

Commissioning for Quality in Rheumatoid Arthritis

DAS

Disease Activity Score

HQIP

Healthcare Quality Improvement Partnership

NICE

National Institute for Health and Care Excellence

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.

