

National Early Inflammatory Arthritis Audit

SDM

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Kim Rezel

Head of Patient and Carer Engagement



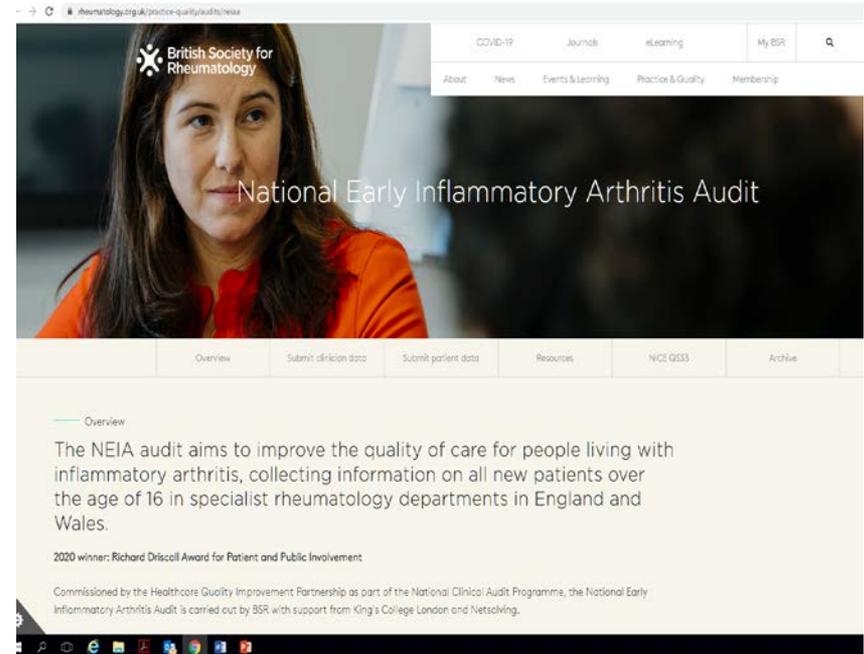
Background and context

- Contacts
 - NEIAA project patient panel
 - National Axial Spondyloarthritis Society (Axial AsA)
 - Versus Arthritis
 - National Rheumatoid Arthritis Society
- Questionnaire
- Focus Group



What we asked about

- Main concerns
- Greatest benefits
- Areas for improvement
- Resources



Main areas of concern

- Appointment flexibility
- Access to urgent care
- Access to advice line
- Variable and inconsistent care
- Female consultant availability
- Psychological interventions
- Not being able to work
- [Rheumatoid Arthritis Distress \(RADS\)](#)

Greatest benefit

- Quick referrals
- Consistent care
- Access to MDT within the community
- Being treated with respect and kindness
- Medication
- Voluntary work
- Peer support
- Transparency

Areas for improvement

- Improved tools for primary care
- The reluctance to prescribe drugs
- Work ability as a measure of treatment
- Staffing in rheumatology
- More transparency
- More psychological support
- Ongoing monitoring – PIFU
- More consistent care including specialist clinics

Addressing diagnostic delay in axial SpA

RHEUMATOLOGY

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Systematic review and meta analysis

Diagnostic delay in axial spondyloarthritis: a systematic review and meta-analysis

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Abstract

Background. Delay to diagnosis in axial SpA (axSpA) is longer than in many other rheumatic diseases. Prolonged delay is associated with poorer outcomes, including functional impairment and quality of life. Our aims were to describe global variation in delay to diagnosis, factors associated with delay, and delay compared with PsA.

Methods. We searched MEDLINE, PubMed, Embase and Web of Science using a predefined protocol. Diagnostic delay was defined as years between the age at symptom onset and at diagnosis. We pooled the mean delay using random effects inverse variance meta-analysis. We examined variations in pooled estimates using prespecified subgroup analyses and sources of heterogeneity using meta-regression.

Results. A total of 64 studies reported the mean diagnostic delay in axSpA patients. The pooled mean delay was 6.7 years (95% CI 6.2, 7.2) with high levels of heterogeneity. Delay to diagnosis did not improve over time when stratifying results by year of publication. Studies from high-income countries

Rheumatology
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REVIEW

Clinical, Economic, and Humanistic Burden Associated With Delayed Diagnosis of Axial Spondyloarthritis: A Systematic Review

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ABSTRACT

Introduction. Few studies have evaluated the impact of delayed diagnosis of axial spondyloarthritis (axSpA) on the overall burden of disease. The objective of this review was to evaluate the available literature on the clinical, economic, and humanistic burden of delayed diagnosis in patients with axSpA.

Methods. This systematic literature review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. We searched the MEDLINE and Embase databases for English-language publications of original research articles (up to July 12, 2018) and conference abstracts (January 1, 2014, to July 12, 2018) reporting studies of adult patients with delayed diagnosis of axSpA associated with clinical,

Enhanced Digital Features To view enhanced digital features for this article go to <https://doi.org/10.6084/m9.figshare.11498697>.

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economic or humanistic burden. Retrieved publications were screened for eligibility by two independent reviewers; discrepancies were resolved by a third independent reviewer. Data were extracted by one reviewer and validated by a second independent reviewer.

Results: A total of 1391 publications were retrieved, of which 21 met the inclusion criteria and were included in the analysis. Of these, 15 reported data on clinical burden, nine on economic burden, and six on humanistic burden, with eight studies reporting a combination of clinical, economic, and/or humanistic burden. Patients with a delayed diagnosis of axSpA generally had higher disease activity, worse physical function, and more structural damage than those who received an earlier diagnosis. Patients with a delayed diagnosis also had a greater likelihood of work disability and higher direct and indirect healthcare costs than those who received an earlier diagnosis. Delayed diagnosis was associated with a greater likelihood for depression, negative psychological impacts, and worse quality of life.

Conclusions: Delayed axSpA diagnosis was associated with more functional impairment, higher healthcare costs, and worse quality of life, highlighting the importance of early recognition of axSpA to reduce extensive burden on patients and society.

Plain Language Summary: Plain language summary available for this article.

△ Ads

Published online: 21 January 2020



Conclusions: Delayed axSpA diagnosis was associated with more functional impairment, higher healthcare costs, and worse quality of life, highlighting the importance of early recognition of axSpA to reduce extensive burden on patients and society.

act on Axial SpA

A programme to achieve a Gold Standard time to diagnosis of one year, following the patient from symptom onset to diagnosis in rheumatology

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Quality Standards for axial SpA

ASAS quality standards for axSpA

Non-rheumatology care			
Clinical symptoms	<u>QS 1: Referral</u> People with suspicion of axial SpA are referred to a rheumatologist for diagnostic assessment within 3 working days		
Rheumatology care			
Diagnosis/ differential diagnosis	<u>QS 2: Time to specialist</u> People with suspicion of axial SpA are assessed by a rheumatologist within 3 weeks after referral	<u>QS 3: Assessment</u> People with suspected axial SpA have their diagnostic work-up completed within 2 months	
Treatment	<u>QS 4: Monitoring disease activity</u> Disease activity of people with axial SpA is monitored under the supervision of a rheumatologist with validated composite scores at least twice a year	<u>QS 5: Disease control</u> In people with axial SpA and active disease despite conventional therapy, treatment escalation with biologics is discussed	<u>QS 6: Non-pharmacological treatment</u> People with axial SpA are informed about the benefits of regular exercise
Management	<u>QS 7: Education and self-management</u> People with axial SpA are offered education on the disease including self-management within 2 months of diagnosis	<u>QS 8: Rapid access</u> Patients with axial SpA and disease flare or possibly drug-related side effects receive advice within 2 working days of contacting the rheumatologist	<u>QS 9: Annual review</u> People with axial SpA have a comprehensive annual review by the rheumatologist

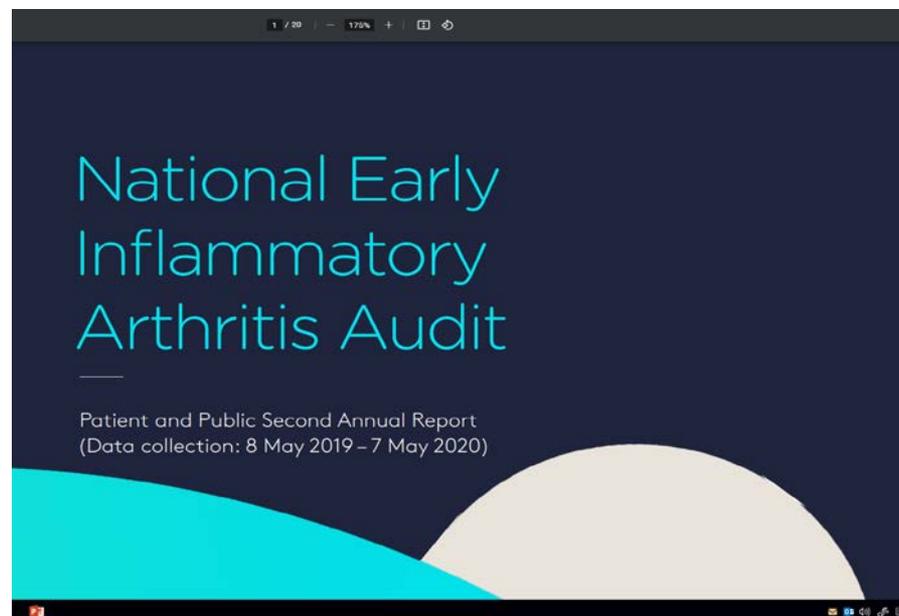
Kiltz U et al. *Ann Rheum Dis.* 2020;79:193–201.

ASAS=Assessment of SpondyloArthritis international Society; axSpA=axial spondyloarthritis.

NICEQS 170

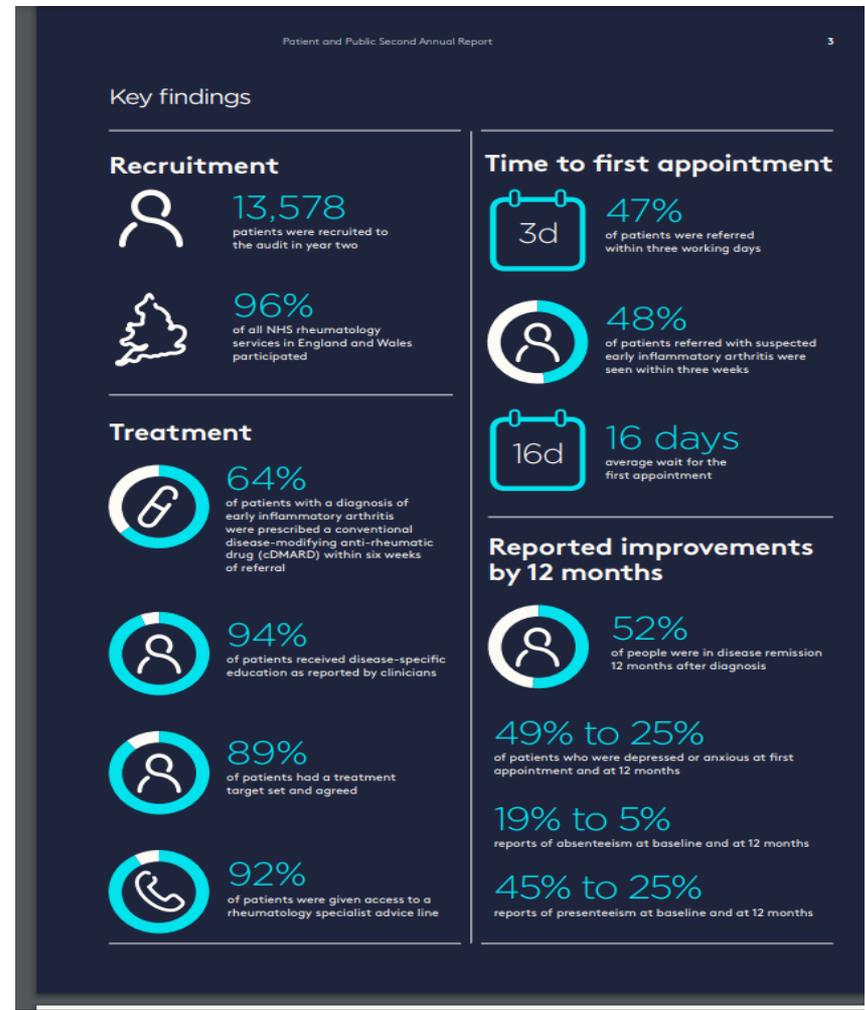
- **Statement 1:** Adults with suspected axial or peripheral spondyloarthritis are referred to a rheumatologist.
- **Statement 2:** Adults with suspected axial spondyloarthritis and an x-ray that does not show sacroiliitis have an MRI, using an inflammatory back pain protocol.
- **Statement 3:** Adults with axial spondyloarthritis are referred to a specialist physiotherapist for a structured exercise programme.
- **Statement 4:** Adults with spondyloarthritis are given information about their condition, which healthcare professionals will be involved with their care, and how and when to get in touch with them

- Information is really useful
- Helps to understand if you're getting the right treatment
- Help patients to be advocates
- Empowers patients in their own treatment



Improvements

- Not a generally recognised condition – more awareness
- not widely disseminated
- more collaborative working with charities
- more accessible
- For the newly diagnosed



- Early diagnosis – patients being listened to
- Patient centred care
- Mental health support
- Ongoing monitoring
- Self management - education