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Acknowledgements

This report was prepared by members of the National Early Inflammatory Arthritis Audit (NEIAA) operations team, using 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. We are very grateful to all the clinical and administrative staff and patients who support and contribute to NEIAA.

**Healthcare Quality Improvement Partnership**

The NEIAA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). 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 in patient outcomes, and to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. The HQIP holds the contract to commission, manage and develop the NCAPOP, comprising over 40 projects covering 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 and, with some individual projects, other devolved administrations and crown dependencies.

**Net Solving**

Established in 2001, Net Solving has spent over a decade perfecting the art of clinical data collection. It has revolutionised the way clinical data collection is conducted by pioneering the move to integrated online data collection methods, leveraging the latest technology to provide highly accurate data collection and analysis. Its market-leading platform CaseCapture™ is the culmination of 15 years’ experience in creating many of the largest clinical data collection web tools in the UK and worldwide. Net Solving is wholly committed to its continuing work with the British Society for Rheumatology (BSR) on the NEIAA project.

**King’s College London**

The Centre for Rheumatic Diseases at King’s College London has provided methodological and analytical support for NEIAA from its outset. It has identified outliers using statistically robust methods and produced the tables and figures in this report.
In 2009, the UK National Audit Office (NAO) reported on the cost-effectiveness of early aggressive treatment of rheumatoid arthritis (RA), and significant geographical variation in RA care across the UK [1]. In the same year, the UK National Institute for Health and Care Excellence (NICE) published clinical guidance (CG79) for the treatment of RA [2], emphasising the importance of early diagnosis and treatment of RA. The NICE guidance has been updated twice since its initial release, in 2015 and 2018 (NG100) [3]. Quality standards for the treatment of RA (QS33) were published in parallel in 2013, and updated in 2018 [4].

The National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis (NCAREIA) was launched in 2014 [5] and was the first comprehensive national benchmarking of care given to people with newly diagnosed inflammatory arthritis. Whilst the audit revealed widespread variation in care and practice, the data enabled services to open a dialogue with commissioners and, in certain cases, secure service improvements by means such as reconfiguration and additional staffing.

The purpose of the NEIAA is to build on this and further improve the quality of care for people living with inflammatory arthritis by measuring care provided to patients against the seven quality statements (QS) set out in NICE quality standard 33 (QS33) [4]. In addition, the NEIAA is now assessing the care quality for patients with inflammatory disease of the spine (axial spondyloarthritis, axial SpA), a subtype of inflammatory arthritis with comparable treatment paradigms. Case ascertainment of confirmed inflammatory arthritis in the first year of the NEIAA was more than double what was captured during the NCAREIA that ran for 21 months.

The audit assesses seven key metrics of care provided for people with new symptoms of arthritis attending rheumatology services for the first time:

1. How quickly do primary care health professionals refer people suspected to have inflammatory arthritis?
2. How soon after referral are people seen in secondary care?
3. How long does it take to start treatment?
4. Do patients receive timely education about their condition?
5. Are treatment targets set and agreed?
6. Do patients have access to emergency advice?
7. Are annual reviews taking place?

The audit also assesses how inflammatory arthritis affects people’s day-to-day function, mobility, sleep, wellbeing and ability to work.
As current President of the British Society for Rheumatology I have great pleasure in sharing the NEIAA’s first annual report, building on the 2014–16 National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

We all know that treating inflammatory arthritis early and effectively improves a patient’s long-term outcomes, reduces long-term disability and benefits society as a whole. The agreed standards may sometimes seem hard to achieve, and my own unit has found itself failing to reach the ideal standard. However, it is important that we can look at our own performance objectively and compare it not just with the agreed standards but also against that of our peers. We can learn from the best practice of others and in the longer term improve our own unit’s performance and reduce regional variation. The rheumatology community has demonstrated its commitment to improvement, with 98% of Trusts/Health Boards participating in the current audit, recruiting 20,668 patients, more than double our target in the first year.

So far, our ability to see patients within three weeks of referral has not improved compared to our previous audit. However, we have reduced the time taken to start effective treatment and increased the proportion of patients receiving early education dramatically. This suggests that we are using our existing resources more effectively and are open to change.

On behalf of the British Society for Rheumatology I would like to extend a thank you to everyone working in rheumatology in England and Wales who has contributed to this valuable audit.

Dr Elizabeth Price
President
The NEIAA collects information on all new patients over the age of sixteen seen in specialist rheumatology departments with suspected inflammatory arthritis in England and Wales. The data presented in this report were gathered from 8 May 2018 to 7 May 2019.

For this report, information is reported on for the first three months of specialist care for all patients with rheumatoid pattern inflammatory arthritis (including psoriatic arthritis of the rheumatoid type) and from the first appointment for all patients with suspected inflammatory arthritis. In future, as follow-up data accrue, the audit will report on data for the first twelve months of specialist care.

Data were entered by clinical teams and by patients with a confirmed diagnosis of inflammatory arthritis.

The audit assesses seven key metrics of care, based on NICE Quality Standard 33, as well as how inflammatory arthritis affects people’s day-to-day function, mobility, sleep, wellbeing and ability to work.

This report provides information on national and regional performance against these standards. Comprehensive breakdowns of Trust/Health Board level performance are provided in the accompanying documents.
1. The NEIAA identified 20,668 patients seen in rheumatology clinics with suspected inflammatory arthritis. Of these, 7,216 (35%) had a subsequent confirmed diagnosis of an inflammatory arthritis. (p12)

2. For a typical rheumatology unit, fourteen patients with suspected inflammatory arthritis were enrolled into the NEIAA each month. (p12)

3. Although referral from primary care is frequently delayed, with only 41% meeting the three-day NICE target, performance has improved significantly since the last phase of this audit and is strongest in Wales. (p22)

4. There are variations across Trusts/Health Boards in staffing ratios. NICE recommended access to specialist allied health professional (AHP) services and early inflammatory arthritis (EIA) pathways. Those with EIA pathways are more likely to have access to specialist AHP services. (p15)

5. Secondary care units take an average of 28 days to achieve first assessment, with performance against the three-week target poorest in Wales. (p24)

6. Since the start of the last phase of this audit in 2014, there have been significant reductions in treatment delay, but disease-modifying anti-rheumatic drug (cDMARD) treatment is still only initiated within six weeks of referral in 54% of patients. (p27)

7. By three months of care there is evidence of clinically meaningful improvement, both in clinician- and patient-reported measures for some patients. (p39)

8. Whilst provision of telephone helplines for patients is high (92%), only 50% of Trusts/Health Boards report on the annual survey of their service structure that they offer emergency access to rheumatology advice within 24 hours. (p36)

9. Patients presenting with inflammatory arthritis have a significant burden of disease, both in terms of physical and mental health. (p38-40)

10. Access to psychology services is limited across all regions. (p14-15)

11. Clinician-reported patient education is provided for 93% of patients. Data collected directly from patients suggested a lower frequency of educational provision of 81%. In some regions the gap between patient- and clinician-reported education was greater (over 20% discrepancy in the West Midlands). (p30)

12. Patients with axial spondyloarthritis (axial SpA) tended to have substantially greater symptom duration prior to assessment, and low levels of referrals from gastroenterology, ophthalmology and dermatology suggest a failure to consider and investigate inflammatory spine disease. (p44)

13. Nearly a third of patients reported significant work impairment at presentation due to their symptoms. This improved over the first three months of care. (p42-43)
Recommendations

**Rheumatology services and providers**
1. Ensure that early arthritis pathways are in place and easily accessible to provide guidance for referrers.
2. Ensure that systems and processes are in place to support rapid initiation of conventional disease-modifying anti-rheumatic drugs.
3. Evaluate workforce needs and expand where required, ensuring access to the full multidisciplinary team.
4. Ensure that rheumatology patients have access to mental health services.
5. Ensure that emergency access (within 24 hours) to advice is available for people with RA.

**Rheumatology services and service users**
6. Work together to increase patient education and self-management support and reduce discrepancy in reported education provision across providers and patients.

**Educators**
7. Promote GP education on the importance of appropriate and timely referrals of patients with suspected EIA. This should include the type of symptoms that should trigger referrals.
8. Promote training to improve mental health comorbidity detection and management in patients with EIA.
9. Promote training for other specialties – gastroenterology, ophthalmology, dermatology – to increase early detection of axial SpA symptoms and prompt referral of patients presenting with these.

**Commissioners and funding bodies**
10. Work with commissioners to evaluate rheumatology workforce and service needs to meet local demand and ensure adequate resources to meet the NICE standards are available.
11. Promote further service improvement via incentives such as the Best Practice Tariff in England.
12. Explore triage mechanisms to reduce referrals for conditions more appropriately managed in primary care.
Interpreting the NEIAA report

Hospital/Unit/Trust participation
All Trusts/Health Boards providing secondary rheumatology care and seeing patients with suspected EIA were eligible to participate. Rheumatology outpatient activity data from NHS Digital and the NHS Wales Informatics Service enabled us to identify all eligible Trusts/Health Boards. NEIAA participation is a contractual requirement for all Trusts/Health Boards in England and Wales, but the project still relies on clinician goodwill for active engagement. It is possible that there may be some bias: departments with less resource and lower historical engagement in quality improvement activities may have found it more challenging to take part.

To encourage participation, webinars were held on a regular basis to offer support on how to register users and navigate the online portal. NEIAA also has a dedicated email address for queries, helping users to access the portal. Trusts/Health Boards that have been identified as non-participants have been approached by BSR and offered support, with a reduction in numbers of non-participating Trusts/Health Boards since audit launch.

Case ascertainment
All patients aged sixteen or over who were first seen in a specialist rheumatology service with suspected EIA between 8 May 2018 and 7 May 2019 were eligible. Rheumatology outpatient activity data allowed us to calculate comparable recruitment rates between Trusts/Health Boards. Currently we have no external method to assess case ascertainment, so there may be sampling bias. Given the better than anticipated levels of recruitment in year one, and the demographic similarities of the sample compared to other large EIA cohorts [6], we believe that any sampling bias is small and does not impact on the validity of the findings.

Data quality and completeness
In order to keep the quality of data high, all information was entered via an online portal. This prompted users to complete mandatory fields, as well as sense checking fields such as NHS number and postcode to ensure they were feasible. As a result, the dataset required minimal cleaning prior to analysis.

Analysis methodology
The report contains performance data for rheumatology services across England and Wales, with breakdown by region\(^1\). Descriptive analyses of patient characteristics across each region are presented using horizontal bar charts. Performance variation at Trust/Health Board level is presented using funnel graphs with individual Trust/Health Board data available in a separate document. This summary report provides information on national and regional performance using horizontal box plots. Funnel graphs plot the percentage of patients achieving a given QS on the y-axis, against the number of patients enrolled by an individual Trust/Health Board on the x-axis. The graphs also provide markers that delineate performance thresholds for Trusts/Health Boards that are outliers at ‘alert’ (two standard deviations [SDs] from the national mean), and ‘alarm’ (three SDs from the national mean) levels.

The more people recruited by an individual Trust/Health Board, the more confident we can be about their performance estimate. This explains why the marker lines come closer together towards the right of the plots.

Box plots are used to display regional performance. The vertical line within the box corresponds to the median value, with the box itself reflecting the interquartile range (IQR). The extended lines represent the upper and lower adjacent values.

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\(^1\) Regions defined by the BSR divisions.
Standards used
Care was assessed against NICE Quality statement 33 for care of patients over the age of sixteen with RA. Details of the standards of care can be found in Table 1.

Table 1. Standards of care.

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<tr>
<th>Statement</th>
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<td>Statement 1</td>
<td>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.</td>
</tr>
<tr>
<td>Statement 2</td>
<td>People with suspected persistent synovitis are assessed in a rheumatology service within three weeks of referral.</td>
</tr>
<tr>
<td>Statement 3</td>
<td>People with newly diagnosed RA are offered conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within three months of onset of persistent symptoms.</td>
</tr>
<tr>
<td>Statement 4</td>
<td>People with RA are offered educational and self-management activities within 1 month of diagnosis.</td>
</tr>
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<td>Statement 5</td>
<td>People who have active RA have their C-reactive protein (CRP) and disease activity measured monthly in specialist care until they are in remission or have low disease activity.</td>
</tr>
<tr>
<td>Statement 6</td>
<td>People with RA and disease flares or possible drug-related side effects receive advice within one working day of contacting the rheumatology service.</td>
</tr>
<tr>
<td>Statement 7</td>
<td>People with RA have a comprehensive annual review that is coordinated by the rheumatology service.</td>
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The probability that a patient achieves QS 1 to QS 3 are estimated using multi-level logistic regression models, which provide an empirical Bayes mean estimate for each individual Trust/Health Board, accounting for local population variation in age, gender, social deprivation, ethnicity and comorbidity. Missing data are accounted for using multiple imputation. For QS 4 to QS 7, estimates are calculated using unadjusted logistic models.
Clinical outcomes
NEIAA reports on clinician- and patient-reported outcomes. Clinicians complete disease activity assessments at baseline, three and twelve months. Patients are asked to complete patient-reported measures at corresponding time points.

The patient-reported measures capture the impact of disease using the Musculoskeletal Health Questionnaire (MSK-HQ), disability using the Health Assessment Questionnaire (HAQ), mental health impact using the Patient Health Questionnaire 4 item Anxiety and Depression Screener (PHQ4ADS), and work using the Work Productivity and Activity Index (WPAI).

Patients can return information through one of three mechanisms: online data entry via the patient audit website (www.myarthritisaudit.org.uk), direct entry with the health care provider in the clinic, or completion of paper forms which are entered online by the clinical team.

Governance including patient involvement
The NEIAA has an independent patient panel, whose view was sought on the data analysis plan, and whose Chair and Deputy Chair sit on the Project Working Group. The NEIAA Senior Governance Group, convened by BSR and including representatives of patient-focused charities, provided methodological oversight and have approved analysis plans.

Small numbers policy
Data for Trusts/Health Boards that have enrolled fewer than five patients into the audit have not been included in this report.

Outlier policy
The NEIAA outlier policy is available online here.
Data quality

Estimating participation
To ascertain evidence of hospital engagement in the audit, and thereby potential for sampling bias in case ascertainment, an estimation of participation is reported. The average (median) number of patients recruited per Trust/Health Board over the twelve months was 171 (IQR 108–263).

Participation is reported according to the number of NEIAA subjects recruited until 7 May 2019 per 1,000 new patient appointments coded to rheumatology clinics in the unit. Rheumatology clinic data are provided by NHS Digital for England and are available for every Trust except Circle Healthcare (Nottingham). NHS Wales Informatics Service (NWIS) is preparing a similar report for Welsh Health Boards, but at present no Welsh data are available.

To provide informative estimates, recruitment rates for Trusts/Health Boards lacking information were estimated using a multiple imputation model using truncated regression with 20 cycles. The imputation model uses organisational data including staffing numbers to inform estimates.

Recruitment rates are heavily right skewed, and so a log transformation was used to calculate alert and alarm status. Alert status was defined as recruitment rates below the 5th centile, and alarm status below the 2nd centile on the log scale. In total, seven Trusts/Health Boards that have recruited at least one patient have significantly lower recruitment rates than expected.

Data completeness and missing data
Baseline records have been created for 20,668 patients. Information is available to calculate performance against QS 1 for 19,369 (94%). Information is available to calculate performance against QS 2 for 20,340 patients (98%). To date 16,671 patients have been recruited who are beyond three months since their first rheumatology appointment; 5,942 (36%) have not yet had eligibility for follow-up (and therefore treatment) confirmed; 5,847 (35%) have a confirmed EIA diagnosis. Information to calculate QS 3 is available for 4,378 patients (75%). Analyses are based on complete cases, with no multiple imputation for missing data.

Multiple imputation relies upon the assumption of the data being missing at random or missing completely at random. Analysis of the previous audit suggests that data may be missing not at random, and therefore the least biased approach would be a non-response imputation, and this model will be developed and evaluated for future reports. However, for this report we have adhered to the model specified in the published analysis plan.

Data accuracy
Data collected for this audit are self-reported by Trusts/Health Boards. At present we are reliant on organisations reporting findings honestly and do not have any current means to externally verify the information submitted.

We check all data fields to ensure plausible values. We are currently not linked to any secondary verification sources (linkage with NHS Digital is due to begin later this year).

You can view our data analysis plan here.
What are we measuring?
Information was collected on the number of consultants, trainees and specialist nurses, as well as availability of EIA services and access to AHP services.

Definition and methods
Organisational data were collected from each Trust/Health Board at the outset of the audit. Data entry was open from May 2018 until August 2018. Staffing ratios and access to AHP services can fluctuate over time, and this information will be collected annually to assess for change. Guidance was provided in help boxes and FAQs on how to calculate whole time equivalents (WTE), but no specific guidance was provided to Trusts/Health Boards with dual academic/clinical consultants. It is possible that academic time has been included in some WTE consultant numbers but a review of consultant staffing levels from academic centres is in keeping with anticipated numbers for clinical time only being included. Further clarification will be made available in help boxes and FAQs for future data collection. Any large fluctuations in consultant levels will be investigated to assess whether academic time has been inappropriately included.

Numbers of new patient appointments for each Trust/Health Board were obtained, as detailed under ‘Data quality’ above, to enable estimation of the denominator population. Due to the overlapping nature of catchment areas and the variation in the services provided, population data were not appropriate to use. Where referral data for Trusts/Health Boards were unusually large or small, we attempted to validate departmental activity through direct correspondence.

What did we find?
We received data from 130/135 (96%) of participating Trusts/Health Boards. The national average ratios of staffing, departmental organisational factors and access to AHP services are detailed in Table 2.

Table 2. Organisational data.

<table>
<thead>
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<th>Structural factor</th>
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<tr>
<td>Consultants, mean (SD)</td>
<td>4.1 (2.1)</td>
</tr>
<tr>
<td>Training grade doctors, mean (SD)</td>
<td>1.3 (1.3)</td>
</tr>
<tr>
<td>SAS doctors, mean (SD)</td>
<td>0.4 (0.6)</td>
</tr>
<tr>
<td>Specialist nurses, mean (SD)</td>
<td>3.4 (1.8)</td>
</tr>
<tr>
<td>Physiotherapy access</td>
<td>122/130 (94%)</td>
</tr>
<tr>
<td>Podiatry access</td>
<td>107/130 (82%)</td>
</tr>
<tr>
<td>Occupational therapy access</td>
<td>123/130 (95%)</td>
</tr>
<tr>
<td>Psychology available in department</td>
<td>50/129 (39%)</td>
</tr>
<tr>
<td>EIA pathway used in department</td>
<td>95/130 (73%)</td>
</tr>
<tr>
<td>Musculoskeletal ultrasound available</td>
<td>123/130 (95%)</td>
</tr>
<tr>
<td>Shared care agreements with primary care for drug monitoring</td>
<td>126/130 (97%)</td>
</tr>
<tr>
<td>Telephone advice line available to patients</td>
<td>126/129 (98%)</td>
</tr>
<tr>
<td>Emergency access to rheumatology advice (within 24 hours) available to patients</td>
<td>64/129 (50%)</td>
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1 Staffing numbers represent whole-time equivalent posts.
The organisational data reported 483 whole time equivalent consultants and 405 whole time equivalent specialist nurses; average (mean) number of consultants across all Trusts/Health Boards was 1.8/1,000 (SD 1.0) and for nurses 1.6/1,000 (SD 0.8). Consultant staffing ratios were highest in London and lowest in Wales and the Southeast (see Figure 1). In contrast, nurse staffing ratios were lowest in London and highest in the Northwest.

Figure 1. Regional staff numbers: consultants and specialist nurses.

Access to occupational therapy, physiotherapy and podiatry was reported by 95%, 94% and 82% of Trusts/Health Boards, respectively. Overall these figures demonstrate an improvement in access to these AHPs since the last report in 2016. However, only 75% of centres can access occupational therapy, physiotherapy and podiatry services (the multidisciplinary team). Centres that have an EIA pathway were more than twice as likely to have access to these multidisciplinary services than centres that do not (odds ratio [OR] 2.7, 95% CI 1.1 to 6.6).

Integrated support for mental health is low, with fewer than half of Trusts/Health Boards reporting access to psychology services in their department.
What does this mean?

Substantial variation exists across Trusts/Health Boards both in terms of structural factors (EIA pathways) and staffing. Some units are particularly well staffed, whilst others appear to be understaffed and the factors behind this finding warrant investigation.

Some Trusts/Health Boards do not have access to any of the NICE recommended specialist AHP services. Access to mental health services is particularly limited across all regions. It is possible that some clinicians are seeking AHP and mental health support via patients’ GPs or external services such as the Improving Access to Psychological Therapies (IAPT) programme.

Despite Trusts/Health Boards reporting near universal provision of a telephone helpline (92%), the annual survey of service structures indicates that urgent rheumatology advice within 24 hours is only available in 50% of Trusts/Health Boards.

Why is this important?

Staffing and structural factors are directly linked to performance against the NICE quality statements. The presence of EIA clinics increased the probability of patients starting cDMARDs in a timely manner by 12% (95% CI 3.7 to 21.5, P = 0.006). Patients seen in an EIA clinic were started on a cDMARD on average eighteen days sooner compared to patients seen in a general rheumatology clinic.

NICE guidelines recommend access to the multidisciplinary team. Inflammatory arthritis is a disabling condition, and research has shown that a holistic approach incorporating occupational therapy, physiotherapy and podiatry leads to improved health outcomes and greater self-efficacy.

The national drive to increase parity of esteem across physical and mental health highlights the importance of access to mental health resources. This is especially relevant to inflammatory arthritis patients who have a greater burden of mental health comorbidity than the general population.
Headlines: Numbers and characteristics of patients referred

What are we measuring?
The number and baseline characteristics of patients referred to rheumatology services in England and Wales between 8 May 2018 and 7 May 2019 were recorded.

Definition and methods
Patients were eligible for entry into the NEIAA if they were referred by their primary care physician (or another non-rheumatology healthcare professional) for assessment of a possible inflammatory musculoskeletal problem. This included both potential peripheral joint and spinal joint problems.

Socioeconomic position data were estimated using a postcode-derived Index of Multiple Deprivation (IMD).

What did we find?
Over twelve months from May 2018 until May 2019, 20,668 patients with suspected inflammatory arthritis were seen in rheumatology services in England and Wales (Figure 2). Recruitment fluctuated by month, with some suggestion that rates reduced slightly in early 2019.

Figure 2. Cumulative enrolment and enrolment by month.

The cohort demographics are representative of an EIA patient group, with a mean age of 54 and female gender predominance (Table 3).

Table 3. Patient demographics.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD)</td>
<td>54 (16)</td>
</tr>
<tr>
<td>Male</td>
<td>7,067/20,668 (34%)</td>
</tr>
<tr>
<td>Female</td>
<td>13,599/20,668 (66%)</td>
</tr>
<tr>
<td>White ethnicity</td>
<td>17,337/20,668 (84%)</td>
</tr>
<tr>
<td>Current smoker</td>
<td>3,463/20,668 (17%)</td>
</tr>
</tbody>
</table>
Socioeconomic position regional variation, represented by the IMD [7], is mapped in Figure 3, demonstrating greater deprivation in the Northeast and Northwest, the Southeast being the least deprived region. England and Wales have deprivation calculated on separate scales. To allow comparability, the mean IMD decile for each region was calculated.

**Figure 3. Socioeconomic position variation across the geographic regions.**

**Regional mapping of average IMD decile**

What does this mean?
The data demonstrate the high demand on rheumatology services attributable to suspected inflammatory arthritis. The demographics are characteristic of an EIA cohort in terms of age and gender.

Why is this important?
These data enable commissioners and healthcare providers to evaluate the demands placed on their rheumatology services and linked workforce requirements. In addition, they provide information on the demographics of patients that need to be cared for.

The demographic and socioeconomic information has been incorporated into the case mix adjusted analyses.
Headlines: Diagnoses of people referred

**What are we measuring?**
The diagnosis and baseline characteristics for all patients. For patients with a diagnosis of a new inflammatory arthritis, additional information was collected including disease severity and comorbidity burden.

**Definition and methods**
Information was gathered for all enrolled patients on the diagnosis established by specialist departments along with patient characteristics including gender, ethnicity and work status.

Comorbidity is assessed using the Rheumatic Disease Comorbidity Index. This is a weighted score validated for use in rheumatic diseases. The score ranges from 0 to 9, with higher scores indicating a greater burden of multimorbidity. RA does not contribute to the score.

**What did we find?**
RA was the most common diagnosis, accounting for 5,234 (27%) of patients recruited with a recorded diagnosis. Mechanical back pain was the second most frequent diagnosis, affecting 3,818 people (20%) (see Table 4 for further detail).

Amongst patients eligible for EIA follow-up (i.e. those with a new diagnosis of inflammatory arthritis with disease warranting initiation of cDMARD therapy with a treat-to-target approach), RA accounted for over two-thirds of patients (see Table 5). Undifferentiated arthritis was the second most common diagnosis, with many of these patients lacking baseline information on serological status (56% with no rheumatoid factor [RhF] or anti-cyclic citrullinated peptide [CCP], compared to 32% missing RhF or CCP in the overall cohort).

**Table 4. Diagnoses of patients referred to rheumatology services.**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number</th>
<th>n = 19,138/20,668 with a recorded diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatoid arthritis</td>
<td>5,234</td>
<td>(27%)</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>1,531</td>
<td>(8%)</td>
</tr>
<tr>
<td>Undifferentiated arthritis</td>
<td>2,089</td>
<td>(11%)</td>
</tr>
<tr>
<td>Axial spondyloarthritis</td>
<td>507</td>
<td>(3%)</td>
</tr>
<tr>
<td>Mechanical back pain</td>
<td>3,818</td>
<td>(20%)</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>3,623</td>
<td>(19%)</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>759</td>
<td>(4%)</td>
</tr>
<tr>
<td>Crystal arthritis</td>
<td>689</td>
<td>(4%)</td>
</tr>
<tr>
<td>Connective tissue disease</td>
<td>278</td>
<td>(1%)</td>
</tr>
<tr>
<td>Reactive arthritis</td>
<td>485</td>
<td>(3%)</td>
</tr>
<tr>
<td>Other</td>
<td>125</td>
<td>(1%)</td>
</tr>
</tbody>
</table>
Compared to the overall cohort, patients with EIA were older. Ethnicity and work status at baseline were comparable to the overall cohort, but the proportion of females was lower (which is surprising, but likely to be explained by the diagnosis heterogeneity). One-fifth of patients were current smokers (higher than the overall NEIAA population), which is relevant given that smoking is a risk factor for both the onset and severity of RA (see Table 6 for more detail).

Table 6. Characteristics of patients with confirmed EIA.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD)</td>
<td>57 (16)</td>
</tr>
<tr>
<td>Male</td>
<td>2,721/7,216 (38%)</td>
</tr>
<tr>
<td>Female</td>
<td>4,494/7,216 (62%)</td>
</tr>
<tr>
<td>White ethnicity</td>
<td>6,266/7,216 (87%)</td>
</tr>
<tr>
<td>Current smoker</td>
<td>1,386/7,216 (19%)</td>
</tr>
<tr>
<td>Greater than 20 hrs work/week</td>
<td>3,414/7,118 (48%)</td>
</tr>
<tr>
<td>Disease features</td>
<td></td>
</tr>
<tr>
<td>Antibody status (RhF or CCP)</td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>3,637/7,216 (50%)</td>
</tr>
<tr>
<td>Negative</td>
<td>2,797/7,216 (39%)</td>
</tr>
<tr>
<td>Not reported</td>
<td>782/7,216 (11%)</td>
</tr>
</tbody>
</table>
The comorbidity burden is low overall but varied substantially amongst patients across geographic regions, with the highest number of patients with comorbidity in Wales and the East of England (see Figure 4). This highlights the need for case mix adjustment as comorbidity may negatively impact on the speed of treatment initiation.

**Figure 4. Regional variation in comorbidity burden amongst patients with EIA (n = 7,084).**

*RDCI = Rheumatic Disease Comorbidity Index. The RDCI is a composite weighted comorbidity measure validated for use in RA epidemiological studies [8].

**What does this mean?**

The proportion of patients recruited who have EIA is in line with expectations. The demographics fit the profile of an EIA cohort.

The high proportion of patients with an ‘undifferentiated EIA’ diagnosis highlights the difficulty in establishing a clear diagnosis from a single specialist consultation for some patients. It is expected that when NEIAA reports on twelve-month data, fewer patients will remain in this category as full diagnostic information is complete.

Whilst most patients do not have comorbidity at diagnosis, comorbidity varies substantially across geographic regions.

**Why is this important?**

Establishing a diagnosis is the first step in a treatment pathway for any patient with EIA, and the factors that can delay diagnosis will be important targets for any quality improvement work linked with this.

GPs may take longer to refer people with multiple health problems as they may attribute new symptoms to pre-existing conditions. Individuals with higher comorbidity burden often need additional investigations prior to safe cDMARD initiation, and this may explain some variation in cDMARD delays across centres. In addition, comorbidity is a negative predictor for treatment response. For these reasons, comorbidity information was used for case mix adjustment.
Quality statement 1: GP referral delays

Compared to the overall cohort, patients with EIA were older. Ethnicity and work status at baseline were comparable to the overall cohort, but the proportion of females was lower (which is surprising, but likely to be explained by the diagnosis heterogeneity). One-fifth of patients were current smokers (higher than the overall NEIAA population), which is relevant given that smoking is a risk factor for both the onset and severity of RA (see Table 6 for more detail).

What are we measuring?
Whether patients with suspected EIA are referred to a specialist within the three working days recommended by NICE. This standard is a measure of primary care performance. Results are adjusted for case mix.

Definition and methods
The number of patients with a ‘YES’ response to the question: “Was referral made within three working days of presentation with EIA symptoms, in accordance with NICE QS 1?” against the total number of patients enrolled.

What did we find?
Data were provided to calculate QS 1 for 19,369/20,668 (94%) of patients. Nationally 7,994/19,369 (41%) of patients were referred within three working days (see Figure 5). QS 1 attainment was highest in Wales, which was also observed in the previous NCAREIA. Adjusted Trust/Health Board QS 1 attainment is shown in the funnel plot (see Figure 6).
What does this mean?
- Referrals from primary care are still not happening in a timely manner for most patients.
- More patients are receiving timely referrals in this phase of the audit when compared to 20% in NCAREIA (second annual report published 2016) [9].
- Achievement rates for this QS continue to be significantly better in Wales.

Why is this important?
Delays in referral from primary care are a key barrier to early treatment initiation. This measure evaluates the primary care contribution to delays in care. Findings serve as an indicator for where further education may be required within primary care.
Quality statement 2: Assessment delays

What are we measuring?
The delay between a rheumatology department receiving a referral for suspected EIA and the date of clinic assessment. Results are adjusted for case mix.

Definition and methods
The number of patients seen within three weeks of receipt of referral is calculated against the total number of patients enrolled. Date of referral was defined as the date provided in response to: “Date referral letter received by Trust/Health Board” and the date seen was defined as “Date of assessment in rheumatology clinic”.

What did we find?
Data were provided to calculate this standard for 20,340/20,668 (98%) of patients. Nationally 7,663/20,340 (38%) of patients referred with suspected EIA were seen within three weeks. Excluding patients ultimately diagnosed with axial SpA or mechanical back pain (4,325 people) did not alter this: 6,131/16,069 (38%). Delays across geographical regions are detailed in Figure 7.

The average (median) assessment delay was 28 days (IQR 17–52). A total of 264 patients waited over six months for assessment, and ten waited over one year. The stacked bar graph demonstrates the variation in waiting times across regions. Adjusted QS 2 performance is shown in the funnel plot (Figure 8).

Patients referred via an EIA pathway had an OR for meeting QS 2 of 2.38 (95% CI 2.24 to 2.54, \( P \lt 0.0001 \)), corresponding to 46% of patients meeting QS 2 who were referred via an EIA pathway, compared to 26% of patients not referred via an EIA pathway. Socioeconomic deprivation was a predictor of not achieving QS 2 (2% lower odds for each decile change [95% CI 1 to 3, \( P \lt 0.0001 \)).

Figure 7. Delay in rheumatology review by geographical region (n = 20,340).
Direct comparison with NCAREIA is not possible due to differing recruitment criteria. A more inclusive approach to recruitment adopted in the NEIAA might have been expected to have a negative impact on performance against QS 2. In NCAREIA, QS 2 performance was 37% [9]. Whilst it is not possible to make a robust inference, it is reassuring that, despite the wider inclusion strategy, QS 2 performance has not worsened.

However, most departments across England and Wales are struggling to see patients in a timely manner. Wales performs the least well for this QS. Northwest has the highest volume activity recorded, but also the highest proportion with a wait of more than six weeks.

Early treatment of inflammatory arthritis reduces the chance of irreversible damage. Rapid treatment of inflammatory arthritis requires pathways that facilitate early assessment in specialist centres.

Factors that are likely to impact on delays in achieving a first specialist appointment and that would be appropriate foci for quality improvement work would include staffing ratios, clinic capacity, processes for handling referrals, collaborative pathways with primary care, service efficiency and patient factors influencing attendance.
Quality statement 3: Treatment delays

What are we measuring?
Time in days to initiation of cDMARD therapy for those patients with a confirmed diagnosis of RA pattern EIA.

Definition and methods
The statement is defined as the number of patients starting a cDMARD within six weeks of referral against the total number of patients enrolled with EIA. Date of referral is defined as the “date referral letter received” and the date cDMARDs started is defined as “What date was treatment started?” either on the baseline or three-month follow-up form (the earliest date only used). cDMARDs needed to be started within 42 days of referral to meet the standard.

NICE QS33 was updated in July 2018, after the NEIAA started. The new NICE QS 33 reads: “People with newly diagnosed RA are offered conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within 3 months of onset of persistent symptoms.” Given that the NEIAA does not record an exact date of symptom onset, the report retains the previous QS 3 definition as defined above. Six weeks from referral to treatment remains a good indicator for specialist care quality.

For this analysis, only patients with a first rheumatology clinic attendance prior to 8 February 2019 were included, to ensure that all patients had exceeded three months of follow-up. As patient cDMARD initiation often occurs on a second visit, the three-month window is essential for accurate calculation of the QS. Use of corticosteroids was not regarded as cDMARD initiation.

What did we find?
Out of the 7,216 patients eligible for EIA follow-up, 5,847 were recruited prior to 8 February 2019. Data were provided to calculate this standard for 4,378/5,847 (75%) of patients. Nationally 2,360/4,378 (54%) of patients with a diagnosis of EIA were established on a cDMARD within 6 weeks of referral.

There was no association between comorbidity burden and QS 3 attainment (OR for QS 3 0.99, 95% CI 0.94 to 1.04, \( P = 0.691 \)). However, the presence of respiratory comorbidity was associated with a lower odds of methotrexate being initiated at baseline (OR 0.85, 95% CI 0.72 to 0.99, \( P = 0.046 \)).

The box plot in Figure 9 shows regional variation in time to cDMARD initiation. Trust/Health Board level variation in QS 3 performance is presented in the funnel plot (Figure 10). Figure 11 indicates that national QS 3 performance has improved during the first year of the NEIAA. A total of 72% of patients eligible for follow-up were given corticosteroids at baseline.
Figure 9. Time to cDMARD initiation by geographical region (n = 4,378).

![Bar chart showing delay in cDMARD initiation by geographical region.](chart)

- National
- Northeast
- Northwest
- Yorkshire & Humber
- East Midlands
- West Midlands
- East of England
- London
- Southeast
- Southwest
- Wales

Proportion of patients (confirmed EIA only)

- cDMARD within 6 weeks
- cDMARD within 8 weeks
- cDMARD delay > 8 weeks

Figure 10. Funnel plot of adjusted QS 3 performance by Trust/Health Board.

![Funnel plot showing QS 3 performance.](chart)
What does this mean?
Most Trusts/Health Boards continue to struggle to establish patients on treatment in a timely manner.

Several Trusts/Health Boards perform very well against this QS and are ‘positive’ outliers. However, some high performers have recruited relatively low numbers to the audit and future work should consider the effects of selective recruitment.

The improvement in performance that started in September 2018 (Figure 11) coincided with the launch of the data visualisation platform on the NEIAA website.

Why is this important?
Delaying the initiation of definitive therapy in newly diagnosed patients with inflammatory arthritis is linked to worse functional impairment, development of irreversible radiological damage within joints, and a lower chance of achieving sustained disease remission in the future.

NEIAA data provide evidence that many Trusts/Health Boards have efficient systems for starting cDMARDs once a patient has been assessed and diagnosed, and there will be shared learning that can be promoted using information from these departments.

Factors that may influence achievement of this QS, and recommended foci for quality improvement work, include timely availability of relevant investigations, specialist nursing staff numbers and patient factors.
Quality statement 4: Education

What are we measuring?
Timely provision of patient education: within the first three months of care patients should receive disease-specific education that encompasses information about their illness, their treatment and self-management.

Definition and methods
Information was collected from clinical teams and from patients with a confirmed diagnosis of RA pattern EIA:

- Clinical teams: The number of patients with EIA who have a ‘YES’ response to the question: “Has disease-specific educational material been offered?”, against the total number of patients enrolled with EIA more than three months prior to 7 May 2019.

- Patients: The number of patients with EIA who have a ‘YES’ response to the three-month follow-up question: “Has disease-specific education, including information on self-management, been provided?”, against the total number of patients enrolled with EIA more than three months prior to 7 May 2019.

Patient-reported data are presented at regional level only, as too few patients responded to provide Trust/Health Board level data.

What did we find?
Clinicians provided data to calculate this standard for 6,993/7,216 (97%) of patients eligible for EIA follow-up. Nationally 6,529/6,993 (93%) of patients with established EIA were offered timely access to education and information on self-management according to information provided from departments. A regional breakdown is detailed in Figure 12.

Data provided directly from patients were available in 1,300/7,216 (18%) of patients. Of these, 1,057/1,300 (81%) reported provision of education by three months. Figure 13 shows both the clinician- and patient-reported data for this QS. Adjusted Trust/Health Board QS 4 attainment is detailed in a funnel plot (Figure 14).

Figure 12. QS 4 (provision of education): performance by geographical region (n = 6,993).
Figure 13. Provision of patient education, patient-reported and clinician-reported.

Figure 14. Funnel plot of adjusted QS 4 performance by Trust/Health Board.
What does this mean?
Timely patient education is provided to most patients but importantly, is not provided to all.

There is a discrepancy between education provision reported by departments compared to patients that warrants further evaluation. This was particularly apparent in the West Midlands.

Why is this important?
Disease education and self-management training has been demonstrated in clinical trials to improve disease outcomes (fatigue, disability) and overall quality of life in patients with RA.

The discrepancy between clinician- and patient-reported education should be an important focus for quality improvement work, with a factor potentially contributing to this finding being the format of education. In addition, what individuals consider adequate education is likely to vary.

Specialist nursing and other AHP staffing ratios are likely factors influencing achievement of this QS.
Quality statement 5: Treatment targets

What are we measuring?
Do clinicians agree a treatment target of low disease activity or remission with patients?

Definition and methods
The number of patients with a confirmed diagnosis of RA pattern EIA who have a ‘YES’ response to the baseline question: “Was a treatment target of low disease activity or remission agreed with the patient?”, against the total number of patients enrolled with EIA.

What did we find?
Data were provided to calculate this QS for 6,952/7,216 (96%) of patients. Nationally 5,843/6,952 (84%) of patients with confirmed EIA had a treatment target set and agreed (see Figure 15 for a regional breakdown). Figure 16 is a funnel plot of adjusted Trust/Health Board QS 5 attainment.

Figure 15. QS 5 (treatment target set and agreed): attainment by geographical region (n = 6,952).
What does this mean?
Most clinicians reported that a shared treatment target was set and agreed with patients. A minority of units (two) have reported no patients receiving an agreed treatment target.

Why is this important?
Agreement of treatment targets is a marker of shared decision-making in clinical practice and gives an indication that clinicians are implementing a treat-to-target approach in managing their EIA patients, as recommended by NICE. Treat-to-target has been shown to be an essential component of care for inflammatory arthritis, resulting in less joint damage and improved quality of life [10].
Quality statement 6: Emergency access to care

What are we measuring?
Are patients provided with contact details for the department in the event of a problem with their disease or treatment?

Definition and methods
The number of patients with a confirmed diagnosis of RA pattern EIA who have a ‘YES’ response to the baseline question: “Has the patient been provided with contact details for a rheumatology specialist advice line?”, against the total number of patients enrolled with EIA.

What did we find?
Data were provided to assess this QS for 6,962/7,216 (96%) of patients. Nationally 6,432/6,972 (92%) of patients were provided with access to rheumatology specialist advice (e.g. a telephone advice line) (see Figure 17 for the regional breakdown). Adjusted Trust/Health Board QS 6 attainment is detailed in a funnel plot in Figure 18.

Figure 17. QS 6 (access to emergency advice): attainment by geographical region (n = 6,962).
Figure 18. Funnel plot of adjusted QS 6 performance by Trust/Health Board.

What does this mean?
Access to urgent advice via a dedicated advice line is available to a majority of newly diagnosed EIA patients, but is not universal. It is possible that Trusts/Health Boards may have developed alternative methods for providing advice, such as a dedicated email address or app.

Organisational data indicate that only 50% of Trusts/Health Boards manage to offer access to urgent rheumatology advice within one working day, despite high availability of advice lines.

Why is this important?
Treatment in EIA involves use of medications that require specialist prescribing and supervision.

Access to clinical advice from a specialist team for any flare-ups of disease or complications from cDMARDs allows for prompt intervention to help reduce the adverse impact of uncontrolled inflammatory disease and rapid change in treatment if cDMARD-related adverse events occur. The risks of drug toxicity are greatest during the early phase of treatment. Access to clinical advice from a specialist team allows timely response to adverse events, ensuring that potentially life-threatening safety signs are not missed. Access to prompt advice is also likely to optimise patient compliance with treatment.
Quality statement 7: Annual reviews

As this is the first annual report, insufficient follow-up has accrued to present data on this standard. Data will be presented in the next report.
Headlines: Disease severity

What are we measuring?
Disease activity of patients with rheumatoid pattern disease was assessed with the Disease Activity Score (DAS28) at baseline and after three and twelve months of follow-up.

Definition and methods
DAS28 is a composite measure that incorporates objective measures of inflammation (number of swollen joints and laboratory markers of inflammation [CRP or ESR]) as well as patient measures (tender joint count and global rating scale of symptom severity) [11]. Scores range from 0 to 10, with remission defined as scores below 2.6, low disease activity 2.6–3.2, moderate disease 3.2–5.1, and severe disease >5.1.

The European League Against Rheumatism (EULAR) DAS28 response is a validated measure of treatment response [12], incorporating both the baseline and follow-up DAS28 scores to stratify patients into ‘good response’, ‘moderate response’ and ‘no response’ groups.

What did we find?
Baseline DAS28 data were available for 6,478/7,216 (90%) of patients eligible for EIA follow-up. At presentation, the mean DAS28 was 4.6 (SD 1.5), within the moderate range, although over a third of people had severe disease at presentation (see Figure 19).

Follow-up DAS28 were available for 3,621/7,216 (50%) of patients. Nationally DAS28 improved in the first three months by an average (mean) of 1.5 (SD 1.6), a change above the minimum clinically important difference (see Figure 20).

By three months, 1,276/3,490 (37%) of patients were in disease remission (activity score below 2.6), and 1,341/3,490 (38%) achieved a good EULAR DAS28 response. A regional breakdown of EULAR DAS28 response is detailed in Figure 21.
Figure 20. Mean DAS28 improvement in first three months by geographical region.

Figure 21. Disease activity response at three months by geographical region.
Attainment of QS 3 (OR 1.4, 95% CI 1.2 to 1.6, $P < 0.001$), initial use of methotrexate (OR 1.2, 95% CI 1.1 to 1.4, $P = 0.005$) and baseline prescription of corticosteroids (OR 1.7, 95% CI 1.4 to 2.0, $P < 0.001$) were associated with achieving a good EULAR DAS28 response at three months.

**What does this mean?**
At the time of diagnosis, most patients reported moderate or severe disease activity scores, which demonstrates a high burden of disease. The pattern of disease activity at presentation is consistent with expectations for RA.

Although there is some regional variation in change in DAS28, the differences are not striking, with all regions achieving well above the minimum clinically important difference for change.

**Why is this important?**
Baseline clinician-reported disease severity provides information on the impact of untreated disease and enables calculation of the magnitude of treatment response at three and twelve months.

Despite a reduction in baseline disease severity since the last audit, over a third of patients still present with severe disease, underlining the importance of prompt referral, review and treatment initiation.
Headlines: Patient-reported outcomes (PROs) including work

What are we measuring?
PROs capturing information on disease impact, functional impairment, mental health and work impact were collected.

Definition and methods
Data were collected from patients with a confirmed diagnosis of RA pattern EIA from their first assessment within specialty services and again after three months of follow-up. Patients could complete information either online via the patient portal or using printed questionnaires available in clinic from the rheumatology department.

PRO data collected:
Musculoskeletal Health Questionnaire (MSK-HQ)
This is a fifteen-item questionnaire evaluating symptom impact. It is validated for use across several musculoskeletal health conditions [13]. A score is calculated from the first fourteen items and ranges from 0 to 56, with higher scores indicating better musculoskeletal health.

Health Assessment Questionnaire (HAQ)
This is a ten-item questionnaire developed four decades ago to measure disability [14]. Scores range from 0 to 3, with higher scores indicating worse functional status.

Mental Health (PHQ4ADS)
These are the two questionnaires that are the standard screening tools recommended for use in the NHS to identify people who have significant depression or anxiety [15, 16]. Each measure contains two items, with a score from 0 to 6. The combined score is a summation of the two components, where higher scores indicate a greater likelihood of mental health comorbidity.

Work status and impact
Impact is assessed using the Work Productivity and Activity Index (WPAI) [17]. Absenteeism is calculated as the number of hours missed as a percentage of total hours worked. Presenteeism is the degree to which a patient’s health impacts on their performance at work. Overall impairment incorporates both absenteeism and presenteeism.

What did we find?
At least one PRO record was available for 3,585/7,216 (50%) of patients at baseline and 1,732/7,216 (24%) at three months. At diagnosis the PRO demonstrates a significant burden of both physical (MSK-HQ and HAQ) and psychological (PHQ4ADS) ill health (see Table 7). 48% of patients returning information met criteria for a probable depression or anxiety disorder.

Over the first three months of treatment, improvement was observed across all PRO measures, with an increase in HAQ above the minimum clinically meaningful difference of 0.22. The percentage of patients meeting criteria for depression or anxiety reduced to just 30% (see Figure 22).

Table 7. PRO measures at baseline.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Patients</th>
<th>Baseline</th>
<th>Three months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Impact (MSK-HQ), mean (SD)</td>
<td>n = 3,051</td>
<td>25.6 (11.5)</td>
<td>34.6 (12.5)</td>
</tr>
<tr>
<td>Disability (HAQ), mean (SD)</td>
<td>n = 2,914</td>
<td>1.1 (0.7)</td>
<td>0.8 (0.6)</td>
</tr>
<tr>
<td>Mental Health (PHQ4ADS), mean (SD)</td>
<td>n = 2,923</td>
<td>4.5 (3.7)</td>
<td>3.0 (3.4)</td>
</tr>
</tbody>
</table>
At baseline there was significant work impairment in terms of absenteeism, presenteeism and overall impairment. Improvements were seen across all three components of the WPAI by three months (see Figure 23). Of the 1,483 patients working for pay, 560 (37.7%) missed work in the previous week due to their health, accounting for 18.9% of their working time (absenteeism). Of the patients working, 43.7% of their work was impaired due to their health (presenteeism).

Figure 23. Work impairment at baseline and three months.
What does this mean?
The return of PRO data was far greater than for the NCAREIA, but much needs to be done to improve the capture of these outcomes.

At presentation, HAQ scores were four times above the mean value in the general population of 0.25 (95% CI 0.22 to 0.28) [18]. Concomitant mental health comorbidity is common, demonstrating the relevance of the parity of esteem agenda within the field of rheumatology.

The reported levels of work impairment at presentation are substantial. Patients are reporting very high rates of absenteeism (18.9%) and presenteeism (43.7%). Although there is improvement by three months, the level of overall impairment remains very significant.

Why is this important?
Patient-reported measures provide vital information about disease impact across a breadth of domains encompassing both physical and mental health. These measures are especially important when considering the availability of AHP support and are a tool for identifying aspects of care for an individual patient that require specific focus.

Historically, collection of PROs and, in particular, mental health information in routine practice is infrequent. Through this audit, systematic mental health data were collected on 2,923/7,216 of patients (40% of EIA patients). This is an important step forward, although there is much room for improvement. The NEIAA Project Working Group and Patient Panel are creating a strategy to improve the proportion of PRO data collected in year 2 of the audit.

Absenteeism has been shown to be associated with work loss in inflammatory arthritis [19]. Work loss is a cause of worse mental and physical health, loss of financial independence and loss of status and purpose in society. It is essential that our clinical targets translate into improved quality of life for patients, including enabling them to retain their work. Measuring and offering support early in the disease course is essential to help patients remain in the workforce.
Axial spondyloarthritis (axial SpA)

What are we measuring?
Axial SpA is a subtype of inflammatory arthritis that results in spinal inflammation and resultant disability. Many of these patients have other manifestations (such as bowel, eye or skin inflammation) and referrals would be expected from other specialists as well as from primary care. NICE has published guidance on referral (NG65) [20].

The route of referral, symptom duration prior to assessment and adherence to referral guidelines, including availability of baseline investigations (HLA B27 antibody testing, imaging), were assessed.

What did we find?
In total 507/20,668 (3%) of referrals were diagnosed with an axial SpA. Most referrals for patients with axial SpA originated from primary care, with a minority from specialists involved in the non-articular presentations of disease (see Figure 24).

Figure 24. Source of referral for axial SpA patients.

Source of referral for Axial SpA patients

Ophthalmology
Dermatology
Gastroenterology
Primary care
Musculoskeletal triage service
Other

In contrast to both RA and mechanical back pain, NEIAA data confirmed patients with axial SpA tended to have substantially greater symptom duration prior to assessment (see Figure 25).
Figure 25. Comparison of symptom duration prior to specialist assessment in rheumatology.

Test results were available for HLA B27 in 281/507 (55%) of patients with a final diagnosis of axial SpA. HLA B27 was positive in 169 (60%). Plain sacroiliac joint X-rays were available in 244/507 (48%), and abnormal in 113 (46%). MRI imaging was available in 258/507 (51%), and positive in 221 (86%).

What does this mean?
The very low number of referrals from gastroenterology, ophthalmology and dermatology suggests that colleagues in these fields may be failing to recognise inflammatory spine disease. The Royal College of Ophthalmologists has published guidelines recommending that unexplained cases of uveal tract inflammation are referred to rheumatology for assessment for axial SpA [21].

HLA B27 testing can help primary care health professionals make appropriate referral decisions as well as inform the specialist about the phenotype of the disease. NICE guidelines recommend testing for HLA B27 in primary care. These data demonstrate that this still does not occur in almost half of cases.

Why is this important?
Axial SpA is a serious disease with substantial patient morbidity. Appropriate referral and prompt diagnosis have the potential to reduce the impact of the disease and prevent long-term spine damage.
Conclusions

The NEIAA has been hugely successful in terms of engagement, with far higher recruitment numbers than anticipated. In addition, the capture of PROs has been above expectations.

The disease burden of inflammatory arthritis is high, although there is already evidence of substantial improvement over the first three months of care in all regions of England and Wales.

Performance against the NICE standards is well below the target of 100%, with continued evidence of regional variation in care. The data provide detailed information needed for local units to understand their performance and support quality improvement. Our findings and recommendations are also consistent with a number of the aims set out in the NHS Long-term Plan 2019 for England – including more joined-up and coordinated care, and support for the increasing number of people with long-term conditions; person-centred care and shared decision-making; increased investment in mental health services; expansion of the NHS workforce; and recognition of the links between health and employment.

Next steps

The audit will continue to collect information on early arthritis care across the NHS. Future reporting will incorporate twelve-month outcome data, including QS 7, as well as linked information from NHS Digital and the NHS Wales Information Service.

Since the outset, we have sought to support those participating in the audit with a range of resources. These include online tools to help units monitor their performance, webinars, quarterly newsletters and regular notifications to those at risk of being outliers. We also have a network of Regional Champions who can offer additional advice and support. We plan to build on what we have learned in the first year and to work with clinicians and our patient panel to support units in improving the care that they offer. Strategies for quality improvement are outlined in the NEIAA quality improvement plan.
Appendices

Appendix 1: Trusts/Health Boards reported as outliers for QS 2
These Trusts/Health Boards were more than two SDs below the mean for QS 2. Those marked with an * are more than three SDs below the mean.

Abertawe Bro Morgannwg University*
Aintree University Hospital NHS Foundation Trust*
Ashford and St Peter’s Hospitals NHS Foundation Trust*
Barts Health NHS Trust
Bolton NHS Foundation Trust*
Brighton and Sussex University Hospitals NHS Trust*
Cardiff and Vale University*
Chelsea and Westminster Hospital NHS Foundation Trust*
Countess of Chester Hospital NHS Foundation Trust
County Durham and Darlington NHS Foundation Trust
Cwm Taf*
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust*
East Lancashire Hospitals NHS Trust*
East Suffolk and North Essex NHS Foundation Trust*
Frimley Health NHS Foundation Trust
Gloucestershire Hospitals NHS Foundation Trust*
Great Western Hospitals NHS Foundation Trust*
Hampshire Hospitals NHS Foundation Trust
James Paget University Hospitals NHS Foundation Trust*
Kingston Hospital NHS Foundation Trust*
Lancashire Care NHS Foundation Trust*
Leeds Teaching Hospitals NHS Trust*
Maidstone and Tunbridge Wells NHS Trust*
Manchester University NHS Foundation Trust
Medway NHS Foundation Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
North Bristol NHS Trust*
North Cumbria University Hospitals NHS Trust*
Northern Devon Healthcare NHS Trust
Northumbria Healthcare NHS Foundation Trust*
Poole Hospital NHS Foundation Trust*
Royal Cornwall Hospitals NHS Trust*
Royal National Orthopaedic Hospital NHS Trust*
Salford Royal NHS Foundation Trust*
Sandwell and West Birmingham Hospitals NHS Trust*
Sherwood Forest Hospitals NHS Foundation Trust*
Staffordshire and Stoke on Trent Partnership NHS Trust
Surrey and Sussex Healthcare NHS Trust*
The Dudley Group NHS Foundation Trust
The Princess Alexandra Hospital NHS Trust*
The Queen Elizabeth Hospital, King’s Lynn, NHS Foundation Trust
The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust*
Torbay and South Devon NHS Foundation Trust
University College London Hospitals NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust*
University Hospitals Bristol NHS Foundation Trust*
University Hospitals of Morecambe Bay NHS Foundation Trust*
Whittington Health NHS Trust*
Wirral University Teaching Hospital NHS Foundation Trust*
Yeovil District Hospital NHS Foundation Trust*
York Teaching Hospital NHS Foundation Trust
Appendix 2: Trusts/Health Boards with <5 patients entered
North Middlesex University Hospital NHS Trust
Powys Teaching Health Board
Western Sussex NHS Foundation Trust

Appendix 3: Non-participating Trusts
Dorset County Hospital NHS Foundation Trust
The Hillingdon Hospitals NHS Foundation Trust
United Lincolnshire Hospitals NHS Trust

Appendix 4: Glossary
AHP  allied health professional
BSR  British Society for Rheumatology
CCP  anti-cyclic citrullinated peptide
cDMARD  conventional disease-modifying anti-rheumatic drug
CI  confidence interval
CRP  C-reactive protein
DAS  Disease Activity Score
EIA  early inflammatory arthritis
ESR  erythrocyte sedimentation rate
EULAR  European League Against Rheumatism
GAD2  Generalised Anxiety Disorder – 2
GIRFT  Getting It Right First Time
HAQ  Health Assessment Questionnaire
HQIP  Health Quality Improvement Partnership
IMD  Index of Multiple Deprivation
IQR  interquartile range
MDT  Multidisciplinary Team
MSK  musculoskeletal
MSK-HQ  Musculoskeletal Health Questionnaire
NAO  National Audit Office
NCAPOP  National Clinical Audit and Patient Outcomes Programme
NCAREIA  National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis
NEIAA  National Early Inflammatory Arthritis Audit
NHS  National Health Service
NICE  National Institute for Health and Care Excellence
NWIS  NHS Wales Informatics Service
OR  odds ratio
PHQ2  Patient Health Questionnaire 2
PHQ4ADS  Patient Health Questionnaire 4 Anxiety and Depression Screener
PRO  patient-recorded outcome
QS  quality statement
RA  rheumatoid arthritis
RhF  rheumatoid factor
SD  standard deviation
WPAI  Work Productivity and Activity Index
Appendix 5: Governance membership

Project Working Group
Dr Jo Ledingham (Chair)
Dr Lesley Kay (Deputy Chair, 2017–19)
Dr Elizabeth MacPhie (Deputy Chair, 2019–20)
Paul Amlani-Hatcher
Prof Fiona Cramp
Martin Cripps
Jessica Ellis
Dr James Galloway
Fowzia Ibrahim
Heidi Lempp
Dr Flora McErlane
Sallie Nicholas
David Pickles
Dr Raj Sengupta
Dr Neil Snowden
Roger Stevens
Dr Karen Walker-Bone
Dr Mark Yates

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Dr Peter Lanyon (Chair, 2017–18)
Ali Rivett (Deputy Chair)
Ailsa Bosworth
Martin Cripps
Dr Benjamin Ellis
Jessica Ellis
Dr James Galloway
Sasha Hewitt
Tasneem Hoosain
Dr Matthew Houghton
Dr Lesley Kay
Dr Jo Ledingham
Dr Alex MacGregor
Sallie Nicholas
Dr Ayas Syed
Sarah Walker
Dale Webb

Patient Panel
Paul Amlani-Hatcher (Chair)
Roger Stevens (Deputy Chair)
Thomas Esterine
Christine Lowe
Hannah Maltby
Carol Simpson
Yvonne Spencer
Kate Wilkins
Ruth Williams
References


