

National Early Inflammatory Arthritis Audit (NEIAA)

Supplementary report presenting data captured at 12 months and results from data linkages (Enrolment window: 8 May 2018-7 May 2019)



Contents

List of tables	4
List of figures	4
Acknowledgements	5
Introduction	6
Executive summary	7
Key findings	8
Interpreting the NEIAA report Data quality	9 11
Headlines: Quality standard 7	12
Headlines: Treatment response	15
Headlines: Patient-reported outcomes	17
Headlines: Unplanned admissions	21
Headlines: Joint replacements and mortality	23
Conclusions	25
Next steps	25
Appendices Appendix 1: Glossary Appendix 2: Governance membership	26 26 27
Project Working Group Patient Panel Senior Governance Group	27 27 27

List of tables

Table 1.	Standards of care
Table 2.	Annual review performance across regions
Table 3.	Disease outcomes at 12 months across regions
Table 4.	Hospital admission rates by region
Table 5.	Joint replacements by region
Table 6.	Regional mortality

List of figures

Figure 1.	Regional QS 7 performance
Figure 2.	Regional breakdown across annual review components
Figure 3.	Use of high-cost drugs by region
Figure 4a.	Patient-reported outcomes: disability (HAQ)
Figure 4b.	Patient-reported outcomes: MSK-HQ
Figure 4c.	Patient-reported outcomes: mental health
Figure 5a.	Work outcomes at diagnosis
Figure 5b.	Work outcomes at three months
Figure 5c.	Work outcomes at 12 months

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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). The 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 the NEIAA from its outset. It has identified outliers using statistically robust methods and produced the tables and figures in this report.

Introduction

The purpose of the NEIAA is to 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** (QS 33).

The NEIAA collects information on all new patients over the age of 16 seen for the first time in specialist rheumatology departments with suspected inflammatory arthritis in England and Wales.

The audit assesses seven key metrics of care:

- 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.

In October 2019, the NEIAA published its **first annual report**. At the time of reporting, insufficient data were available to report on the seventh metric (annual reviews), as most patients would have had less than 12 months of follow-up. The purpose of this supplementary report is to provide information on this seventh metric alongside 12-month clinician- and patient-reported outcome data. Linkage to NHS Digital enables reporting for the first time on unplanned hospitalisations, joint replacements and all-cause mortality.

Executive summary

This report covers information about the first 12 months of specialist care for all patients with rheumatoid pattern inflammatory arthritis (including psoriatic arthritis of the rheumatoid type). This includes both clinician- and patient-reported outcomes at baseline, three and 12 months.

The report provides information on national and regional performance against QS 7, as well as unplanned hospital admissions, joint replacements and mortality. As the NEIAA dataset matures, the data obtained from data linkages will provide robust measures of clinical outcomes to add to the clinician- and patient-reported outcomes.

For this report the outcomes of patients enrolled into the audit between 8 May 2018 and 7 May 2019 who have had 12-month information returned were examined. Any 12-month data received up to 1 December 2019 have been included.

Key findings

- There is evidence of substantial reduction in disease burden, as measured by clinician Disease Activity Scores (DASs) and patient-reported outcomes (PROs), over the first 12 months of care in all regions of England and Wales.
- 2. In total, 779/1,448 (54%) patients were in remission 12 months after diagnosis.
- Patients treated with disease-modifying anti-rheumatic drugs (DMARDs) within six weeks of referral had a greater chance of being in remission at 12 months: odds ratio (OR) 1.36, 95% confidence interval (CI) 1.04 to 1.77.
- 4. PRO data show improvements in measures of disability, mental health and ability to work. Over 12 months of specialist care, Musculoskeletal Health Questionnaire (MSK-HQ) scores increased by over 12 units, double the minimum clinically important difference.
- 5. Targeted treatment was started within 12 months of specialist care in 15% of patients. The term targeted therapy in rheumatology implies the group of high-cost specialist drugs such as anti-Tumour Necrosis Factor (TNF) and Janus Kinase (Jak) inhibitors. We used to term these 'biologics', but the launch of the JAK inhibitors complicates things as technically they are not biologics, hence the use of the new term.
- 6. Clinicians reported that an annual review was performed for only 43% of patients. This is an area which needs further work to understand the reasons and implications.
- Data linkage to hospital episodes statistics (HES) and mortality data has shown, for the first time, that within the first 12 months of diagnosis of inflammatory arthritis:
 a. There is a high burden of unplanned admissions
 - b. There are relatively low levels of joint replacement and mortality
- 8. Despite the positive headlines, it is important to acknowledge that substantial regional variation has been shown in both QS performance and outcomes, including remission rates, use of high-cost drugs and unplanned admissions.

Interpreting the NEIAA report

Hospital/unit/Trust participation

All Trusts/Health Boards providing secondary rheumatology care and seeing patients with suspected early inflammatory arthritis (EIA) were eligible to participate. Rheumatology outpatient activity data from NHS Digital and the NWIS 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. As previously highlighted, some bias is possible: departments with less resource and lower historical engagement in quality improvement activities may have found it more challenging to take part.

Case ascertainment

All patients aged 16 or over who were first seen in a specialist rheumatology service with suspected EIA between 8 May 2018 and 7 May 2019 were eligible. The annual report published in October 2019 presents recruitment rates for Trusts/Health Boards. There is currently no external method to assess case ascertainment, so sampling bias is possible. Given the better than anticipated levels of recruitment in year one, and the demographic similarities of the sample compared to other large EIA cohorts, it is believed 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 checking fields such as NHS number and postcode to ensure they were credible.

Analysis methodology

The report contains performance data for rheumatology services across England and Wales, with breakdown by region¹. The previous annual report has provided descriptive analyses of patient characteristics across each region, funnel graphs to show performance variation at Trust/Health Board level, and details of individual Trust/Health Board data. This report provides information on national and regional performance using horizontal box plots.

Data linkage

Deterministic matching to NHS Digital and the NWIS of all patients with EIA with a valid NHS number was performed to link to hospital episodes (including joint replacements) and mortality for England and Wales. No patients were flagged as opt-outs in England or Wales.

Standards used

This audit assesses achievement of the **NICE QS 33** statements for care of patients over the age of 16 with rheumatoid arthritis (RA). Details of the standards of care set out in the statements can be found in **Table 1**.

Table 1. Standards of care

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

For this report, only QS 7 is reported on.

Clinical outcomes

The NEIAA reports on clinician- and patient-reported outcomes. Clinicians complete disease activity assessments at baseline, three and 12 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 four-item Patient Health Questionnaire 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 healthcare 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 has 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.

Data quality

Data completeness and missing data

Clinicians and patients were able to submit data for the 12-month review at any time between 10 and 14 months from the date of first assessment. Any 12-month data submitted by 1 December 2019 are included in this report.

At the time of preparation, 7,493 patients with a confirmed diagnosis of EIA had been recruited to the audit within the 12 months from 8 May 2018 until 7 May 2019. Of these, 3,296 patients had been registered more than 12 months ago. Of these patients, 1,524/3,296 (46%) had 12-month audit information returned. PRO information was available for 629/1,524 (41%) patients.

A total of 6,745/7,493 (90%) patients had NHS numbers that could be used for linkage with NHS Digital or NWIS data.

Data accuracy

Data collected for this audit include self-reported information from Trusts/Health Boards as well as linked data from NHS Digital and the NWIS. At present the NEIAA is reliant on organisations submitting self-reported findings honestly and does not have any means to externally verify the information submitted. All data fields are checked to ensure plausible values. You can view our data analysis plan **here**.

Headlines: Quality standard 7

What are we measuring?

We are measuring whether patients had had an annual review 12 months after diagnosis. Additional information was gathered when an annual review had taken place.

Definition and methods

We collected information for individual patients via a clinician questionnaire approximately 12 months after diagnosis. Clinicians were sent reminders at 12 months to notify them that the information was due. We accepted a two-month window either side of the 12-month time point for data collection. We did not gather information on where the annual review took place (i.e. in the primary or secondary care setting), but simply whether the review had been performed.

If an annual review had taken place, we asked whether three specific components were included: an assessment of bone health (e.g. FRAX score), a cardiovascular risk assessment (e.g. QRISK3) and an assessment of disability (e.g. HAQ score). We did not record actual scores.

What did we find?

In total, 1,524 patients from the first year of data collection had data returned on annual review status (see **Table 2**). Of these, 648 (43%) had an annual review undertaken and 876 (57%) had not (see **Figure 1**). Data were not yet returned or missing for 1,772/3,296 (54%) patients recruited more than 12 months ago. Regional variation in annual review completion ranged from 15% in London to 68% in the East Midlands.

Of people who did have an annual review, 407/648 (63%) included a bone health assessment, cardiac risk assessment and disability. Only 96/648 (15%) had all three components assessed. **Table 2** shows the regional variation. The individual components are reported as a percentage of those people who had an annual review completed (see also **Figure 2**). There was no clear pattern concerning which components of the annual review were included.

Region	Total reported	Annual review	Cardiac risk assessed	Bone health assessed	Disability assessed
National	1523	43%	35%	41%	40%
Northeast	80	40%	47%	59%	34%
Northwest	224	35%	31%	56%	38%
Yorkshire & Humber	153	52%	28%	27%	38%
East Midlands	155	68%	32%	51%	53%
West Midlands	205	49%	22%	42%	38%
East of England	133	41%	36%	25%	16%
London	151	15%	39%	61%	43%
Southeast	214	43%	43%	26%	36%
Southwest	141	42%	48%	40%	40%
Wales	67	34%	43%	35%	87%

Table 2. Annual review performance across regions







What does this mean?

We can only comment on the patients who have had information returned for their 12month assessment. However, considering only those for whom we have information, a majority of clinicians reported that an annual review had not been undertaken. When clinicians indicated that an annual review had been done, it frequently did not include all three of the domains this audit assessed (bone health, cardiovascular risk assessment and disability review).

Further investigation of the reasons for these findings is warranted as there are many potential explanations. It is possible that there are differences in the interpretation of the NICE guideline, or differences in the interpretation of the NEIAA question. Further work is needed to understand what processes are in place/being implemented for annual reviews and the obstacles to providing this service to patients.

Why is this important?

RA increases cardiovascular risk, fracture risk and the risk of disability. The goal of rheumatology care is to minimise any adverse outcomes linked to the disease. An annual review has been a recommendation from NICE for many years, in recognition of the importance of delivering a structured and individualised review to highlight specific risks and care needs. Patient organisations have strongly supported the value of this process to patients and questioned to what extent it has been made available to patients.

Headlines: Treatment response

What are we measuring?

The disease activity of patients with rheumatoid pattern disease was assessed with the Disease Activity Score (DAS28) at baseline and after three and 12 months of follow-up. Data on the baseline and three-month time points were published in the first annual report. This report presents the 12-month information.

In addition, we report on the proportion of people escalated to targeted therapies (e.g. biologics) by 12 months.

Definition and methods

The 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). Scores range from 0 to 10, with remission defined as scores below 2.6, low disease activity as 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, incorporating both the baseline and follow-up DAS28 scores to stratify patients into 'good response', 'moderate response' and 'no response' groups.

Multivariable logistic regression was used to describe associations with remission at 12 months.

What did we find?

Data were available to calculate disease activity on 1,448/1,524 (95%) patients (see **Table 3**). At 12 months, 779/1,448 (54%) patients were in a state of disease remission. The breakdown according to EULAR response is shown in **Table 3**. Remission rates vary across regions, with lower rates in the Northwest and Wales, and the highest attainment of remission in the Southeast.

Data were available on transition to targeted therapy in all 1,524 patients. Only 229/1,524 (15%) patients were started on a targeted therapy by 12 months (see **Figure 3**). Transition to a targeted therapy ranged between 10% in Yorkshire & Humber and 20% in the Southeast and East of England. Targeted therapies include biologic DMARDs and Janus kinase (JAK) inhibitors, and are considered high-cost relative to cDMARDs.

Region	Total reported	Remission	EULAR good response	EULAR moderate response	EULAR no response
National	1447	54%	57%	22%	21%
Northeast	77	62%	61%	29%	10%
Northwest	202	48%	54%	25%	21%
Yorkshire & Humber	140	51%	54%	23%	23%
East Midlands	152	56%	55%	25%	20%
West Midlands	200	52%	57%	22%	21%
East of England	125	55%	61%	19%	20%
London	145	43%	49%	24%	27%
Southeast	204	62%	62%	15%	23%
Southwest	137	59%	60%	20%	20%
Wales	65	54%	66%	22%	13%

Table 3. Disease outcomes at 12 months across regions



What does this mean?

DAS28 remission rates at 12 months are good, with a greater proportion in remission than is seen in most contemporary clinical trials. The variation is substantial, however, and suggests that there are important differences in outcome depending upon where a person is treated.

The use of targeted therapies also varies substantially by region. The differences are not explained by differences in disease severity (either at baseline or during follow-up), suggesting variation in practice.

Why is this important?

Clinical outcomes are the ultimate measure of the value and impact of care. It is important to understand the relationship between process and clinical outcomes, and measuring both via the NEIAA will improve our understanding.

Remission is the ultimate clinical target. NEIAA data show that patients treated with DMARDs within six weeks of referral (QS 3) had a greater chance of remission at 12 months: OR 1.42; 95% Cl 1.14 to 1.76. Starting treatment within six weeks of referral was nine times more likely (OR 9.0; 95% Cl 7.9 to 10.2) if the first appointment occurred within three weeks of referral (QS 2).

In an adjusted model male gender was associated with an increased chance of remission (OR 1.7, 95% Cl 1.3 to 2.2). Comorbidity and socioeconomic deprivation were both associated with a reduced chance of remission. One unit increase on the Rheumatic Disease Comorbidity Index (RDCI) was associated with an OR of 0.8 (95% Cl 0.7 to 0.9). One decile change on the Index of Multiple Deprivation (IMD) was associated with a reduced OR of 0.93 (95% Cl 0.89 to 0.97).

The data also show that, after 12 months of care, there is regional variation in outcomes and a significant number of patients fail to achieve clinical response. More work is required to close the gap in achieving remission and treatment response across regions. Targeted treatments have been a major advance in the treatment of inflammatory arthritis resistant to cDMARDs. Targeted treatment options include biologics, e.g. Tumour Necrosis factor (TNF) inhibitors and JAK inhibitors and represent a class of drugs that are high cost. There are restrictions imposed by NICE on their use, but they should be available to all patients with treatment-resistant disease within a 12-month interval from diagnosis. There are likely to be many reasons for the substantial variations in use shown by the NEIAA data, and this variation warrants further investigation.

Headlines: Patient-reported outcomes

What are we measuring?

PROs capturing information on disease impact, functional impairment, mental health and work impacts 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 and 12 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 15-item questionnaire evaluating symptom impact. It is validated for use across several MSK health conditions. A score is calculated from the first 14 items and ranges from 0 to 56, with higher scores indicating better MSK health.

Health Assessment Questionnaire (HAQ)

This is a 10-item questionnaire developed four decades ago to measure disability. Scores range from 0 to 3, with higher scores indicating worse functional status.

Mental Health (PHQ4ADS)

These are the two questionnaires (PHQ2 and GAD2) that are the standard screening tools recommended for use in the NHS to identify people who have significant depression or anxiety. Each measure contains two items, with a score from 0 to 6. The combined score (PHQ4ADS) 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). Absenteeism is calculated as the number of hours missed as a percentage of total hours contracted to work. 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?

PROs were available for 629/1,524 (41%) of patients. On average, patients reported improvements over 12 months across all domains evaluated (disease impact, physical function, mood, work). The figures below provide the details for each outcome.

MSK-HQ scores improved (see **Figure 4b**) from a mean of 25.6 at baseline to 37.4 at 12 months, a change well above the minimum clinically important difference (MCID) of 5.5 for the measure. In parallel, disability levels reduced over the period, with a mean difference between baseline and 12 months of 0.41, almost double the MCID of 0.22 (see **Figure 4a**).

Mental health comorbidity was frequent (see **Figure 4c**), with almost half (48.9%) of patients screening positive on the combined PHQ2/GAD2 tool at diagnosis. By 12 months, only 26.5% screened positive, which is only marginally above the background population rate.

Overall work impairment (see **Figure 5**) reduced from 31.9% at baseline to 23.5% at 12 months. While this demonstrates substantial improvement, it is below the estimated MCID of 20% for this measure.

Figure 4a. Patient-reported outcomes: disability (HAQ)







Figure 4c. Patient-reported outcomes: mental health



Proportion of patients screening positive for mental health comorbidity



Figure 5b. Work outcomes at three months











Only the national statistics can be presented here due to the low volume of data available thus far but, as with other NEIAA assessments of care, regional variation in PROs is evident so work still needs to be done to reduce variation.

What does this mean?

These data provide a great source of optimism, demonstrating the benefits of NHS care, with some striking improvements across England and Wales as a whole. This is one of the largest studies to demonstrate such remarkable improvements across the domains of PROs.

Why is this important?

The NEIAA patient-reported measures provide information about disease impact across a breadth of domains, encompassing both physical and mental health as well as impact on work. It is essential that our clinical targets translate into improved quality of life for patients and that we are assessing measures that are important to patients.

Historically, collection of PROs and, in particular, mental health and work information is infrequent in routine practice.

There is a recognised association between work loss and absenteeism with inflammatory arthritis. Work loss is a cause of worse mental and physical health, loss of financial independence and loss of status and purpose in society. Measuring and offering support early in the disease course is essential to help patients remain in the workforce.

This audit highlights the importance of mental health comorbidity. The wider agenda for parity of esteem across physical and mental health is particularly relevant to patients with inflammatory arthritis, who experience a significantly greater burden of mental health comorbidity than the general population.

There is much room for improvement, but the NEIAA has triggered data capture directly from patients and shown that it is possible to collect this information to guide management decisions, making this an important step forward for the rheumatology community and its patients.

Headlines: Unplanned admissions

What are we measuring?

How often are patients admitted to hospital for unplanned care following a diagnosis of EIA?

Definition and methods

All patients with a confirmed diagnosis of EIA with a valid NHS number uploaded to the NEIAA were linked to NHS Digital and the NWIS. The number of unplanned admissions (including attendances at emergency departments) was recorded. Event rates per 1000 patient years were calculated. Cox proportional hazards models were used to describe associations with unplanned admissions.

What did we find?

In total, 343 patients had an unplanned admission (see **Table 4**). The national unplanned admission rate was 159 per 1000 person years (95% Cl 143 to 177), with rates ranging from 112 in the Southeast to 207 in the East Midlands.

Table 4. Hospital admission rates by region

Region	Unplanned admission rate/1000 person years	Lower 95% Cl	Upper 95% Cl
National	158.8	142.9	176.5
Northeast	153.1	98.8	237.3
Northwest	171.3	131.8	222.5
Yorkshire & Humber	196.4	144.1	267.7
East Midlands	206.6	150.4	284.0
West Midlands	128.2	89.6	183.4
East of England	150.0	104.3	215.9
London	145.7	104.6	203.0
Southeast	111.8	79.9	156.4
Southwest	166.5	119.6	231.9
Wales	197.6	134.5	290.2

What are we measuring?

Approximately 1 in 7 people diagnosed with EIA will have an unplanned admission within 12 months of diagnosis. In an adjusted analysis, the only patient characteristic that predicted hospitalisation was the presence of comorbidity (hazard ratio: 1.3 per unit RDCI change; 95% CI 1.1 to 1.4).

Why is this important?

Unplanned admissions represent a need for prompt medical review and an unpredictable demand for NHS support. People with newly diagnosed inflammatory arthritis may need to be seen urgently in hospital for a number of reasons (flares of arthritis, complications of treatment [side-effects, infections], inter-current illnesses or for unrelated medical problems) and these data provide clear evidence of variation in rates of unplanned admissions across regions.

The association with comorbidity is important, as this varies by region and is therefore an important contextual factor when considering site-level variation.

This is the first time that anyone has reported on admission data for an EIA cohort in this manner. The information provides an important benchmark against which performance can be measured in the future.

This report does not explore reasons for hospitalisation, although work is ongoing to explore specific patterns in admission, in particular looking at infections.

Headlines: Joint replacements and mortality

What are we measuring?

We have measured (a) how often patients require joint replacement surgery and (b) mortality rates within 12 months of diagnosis of EIA.

Definition and methods

All patients with a confirmed diagnosis of EIA with a valid NHS number uploaded to the NEIAA were linked to NHS Digital and the NWIS. The number of hip or knee joint replacements as well as any deaths were recorded. Event rates per 1000 patient years were calculated.

What did we find?

In total, 19 people had a joint replacement (see **Table 5**), corresponding to a rate of 8/1000 per year (95% Cl 5 to 13). The highest rate was observed in the West Midlands, and three regions (East Midlands, East of England and Wales) reported no joint replacements.

Table 5. Joint replacements by region

Region	Joint replacements/ 1000 person years	Lower 95% Cl	Upper 95% Cl
National	8.3	5.3	13.1
Northeast	7.3	1.0	51.8
Northwest	5.7	1.4	22.9
Yorkshire & Humber	9.3	2.3	37.1
East Midlands	0.0		
West Midlands	24.4	11.0	54.3
East of England	0.0		
London	11.9	3.8	36.8
Southeast	9.4	3.0	29.2
Southwest	9.1	2.3	36.6
Wales	0.0		

In total, 42 deaths occurred (see **Table 6**), corresponding to a mortality rate of 18/1000 per year (95% Cl 14 to 25). Mortality was highest in the Northeast, and lowest in London.

Table 6. Regional mortality				
Region	Mortality/1000 person years	Lower 95% Cl	Upper 95% Cl	
National	18.4	13.6	24.9	
Northeast	29.2	11.0	77.8	
Northwest	20.0	9.5	42.0	
Yorkshire & Humber	27.8	12.5	61.8	
East Midlands	15.3	4.9	47.4	
West Midlands	20.2	8.4	48.5	
East of England	19.5	7.3	51.9	
London	3.9	0.6	28.0	
Southeast	18.8	8.4	41.8	
Southwest	16.2	6.1	43.0	
Wales	7.1	1.0	50.2	

Based upon the limited numbers of events accrued to date, numbers are too low for the NEIAA to present Trust/Health Board level event rates for joint replacement and mortality (as no individual Trust/Health Board has had >5 events).

What does this mean?

Very few people have joint replacements in the first 12 months after diagnosis, which is to be expected given that joint damage such that replacement is required takes time to accumulate. It is important to recognise that several factors contribute to joint replacements, including clinical need for surgery and access to surgery. Areas where no joint replacements were undertaken could reflect a lack of need or long waiting times for surgery.

The mortality data are crude estimates, and do not account for case mix. Demographics and comorbidity are important to consider, e.g. London has the youngest population of all regions.

Why is this important?

Inflammatory arthritis has long been associated with a need for joint replacement surgery and reduced life expectancy. General epidemiological studies have suggested a trend towards fewer joint replacements and a mortality rate that is approximately that of the general population in recent years. The low numbers of events across England and Wales as a whole suggest that this trend is being seen in practice and is reassuring. It is vital, however, that we continue to review these data and work towards good outcomes being translated to all patients in England and Wales.

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, even 12 months after first appointment
- Available data suggest a problem in delivering annual reviews for most people with inflammatory arthritis
- The disease burden of inflammatory arthritis is high, although there is evidence of substantial improvement over the first 12 months of care in all regions of England and Wales
- Relatively low numbers of patients progress to targeted treatment within 12 months of their first specialist assessment
- There is a high burden of unplanned admissions within the first 12 months of receiving a diagnosis of an inflammatory arthritis. Work is needed to understand what the drivers are for these and to ascertain whether they are avoidable
- The joint replacement and mortality data provide insight into some of the most impactful measures available to an early arthritis population
- As the NEIAA dataset matures, the data obtained from data linkages will provide robust measures of clinical outcomes to add to the clinician- and patient-reported outcomes
- The data provide detailed information needed for local units to understand their performance and support quality improvement activity
- Substantial regional variation has been shown for all aspects of care presented in this report

Next steps

The audit will continue to collect information on early arthritis care across the NHS. Future reporting will incorporate 12-month outcome data alongside the baseline and three-month results.

Strategies for quality improvement are outlined in the **NEIAA quality improvement plan**.

Appendices

Appendix 1: Glossary

BSR	British Society for Rheumatology
cDMARD	conventional disease-modifying anti-rheumatic drug
CI	confidence interval
CRP	C-reactive protein
DAS	Disease Activity Score
DMARD	disease-modifying anti-rheumatic drug
EIA	early inflammatory arthritis
ESR	erythrocyte sedimentation rate
EULAR	European League Against Rheumatism
GAD2	Generalised Anxiety Disorder 2
HAQ	Health Assessment Questionnaire
HQIP	Health Quality Improvement Partnership
IMD	Index of Multiple Deprivation
IQR	interquartile range
JAK	Janus kinase
MCID	minimum clinically important difference
MSK-HQ	Musculoskeletal Health Questionnaire
NCAPOP	National Clinical Audit and Patient Outcomes Programme
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
RDCI	Rheumatic Disease Comorbidity Index
SD	standard deviation
WPAI	Work Productivity and Activity Index

Appendix 2: Governance membership Project Working Group

Dr Jo Ledingham (Chair) Dr Elizabeth MacPhie (Deputy Chair) Paul Amlani-Hatcher Prof Fiona Cramp Martin Cripps Jessica Ellis Dr Jill Firth Dr James Galloway Dr Ian Giles Fowzia Ibrahim Dr Flora McErlane Sallie Nicholas David Pickles Dr Raj Sengupta Dr Charlotte Sharp Roger Stevens Prof Karen Walker-Bone Dr Mark Yates

Patient Panel

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

Senior Governance Group

Dr Elizabeth Price (Chair) Ali Rivett (Deputy Chair) Ailsa Bosworth Martin Cripps Dr Benjamin Ellis Jessica Ellis Dr James Galloway Sasha Hewitt Tasneem Hoosain Clare Jacklin Dr Peter Lanyon Dr Jo Ledingham Dr Gary MacFarlane Dr Elizabeth MacPhie Sallie Nicholas Dr Ayas Syed Sarah Walker Dale Webb



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