

# National Early Inflammatory Arthritis Audit (NEIAA)

Second Annual Report

(Data collection: 8 May 2019 - 7 May 2020)



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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 grateful to all the clinical and administrative staff and patients who support and contribute to the 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 audits, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the NCAPOP, including 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, using the latest technology to supply 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 committed to its continuing work with 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

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. Quality standards for the treatment of RA (QS33) were published in parallel in 2013, and these were most recently updated in 2020 [3].

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 (QS33) [3]. In addition, the NEIAA assesses the care quality for patients with inflammatory disease of the spine (axial spondyloarthritis, axial SpA), a subtype of inflammatory arthritis with comparable treatment paradigms.

The audit assesses seven key metrics of care 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 prompt 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 well as reporting on clinical outcomes including hospitalisations, joint replacements and mortality.

### **Foreword**

As current BSR President I have great pleasure in sharing the NEIAA's second annual report, building on the first annual report and on the 2014–16 National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis (NCAREIA).

All healthcare services have experienced unprecedented challenges linked to the COVID-19 pandemic in 2020 and will face further challenges as rheumatology teams continue to be redeployed to support other services. The data collection period for this report was curtailed due to the pandemic but the majority of the data presented were collected prior to any major impact on NHS services.

The continued excellent engagement with this audit is a testament to the rheumatology community's willingness to assess the quality of the services it provides. The significant improvements in performance against the first three **NICE quality statements**, targeted within the quality improvement plan, also reflects a commitment to work to achieve improvement.

I am delighted to see that patients have also engaged well and that we now have important patient-derived information on outcomes to help guide our decisions on early inflammatory arthritis (EIA) care.

It is too early to draw any conclusions from the additional data on mortality, joint surgery and unplanned admissions but this is an exciting development since the publication of the last annual report. These data will increasingly provide us with important information on the impact of EIA services.

The data presented in this report, whilst providing some grounds for optimism, also highlight aspects of care requiring more focus. The challenges to the rheumatology community will be huge as we move forward with new ways of working and the audit will need to adapt to this. I understand the immense pressure that NHS staff are under but hope that you will find some time to read the report and re-engage with the audit at the earliest opportunity so that the audit team can assess the impact of the COVID-19 pandemic on rheumatology patient care.

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

**Dr Sanjeev Patel**BSR President

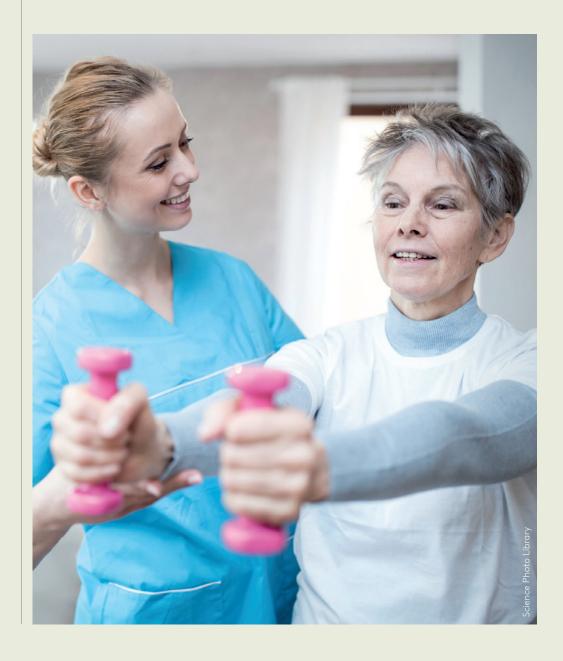
# **Executive summary**

The NEIAA collects information on all new patients over the age of 16 seen in specialist rheumatology departments with suspected inflammatory arthritis in England and Wales. The data presented in this report were gathered from 8 May 2019 to 7 May 2020. Data collection was non-mandatory from 27 March 2020 due to the COVID-19 pandemic and therefore data analysed predominantly reflects activity prior to the major impact of COVID-19.

Information is reported for the first 12 months of specialist care for 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.

The audit assesses seven key metrics of care, based on **NICE Quality Standard 33**. In addition, it assesses clinical outcomes and 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 and on outcomes. Comprehensive breakdowns of Trust/Health Board level performance are provided in accompanying documents.



# Key findings

- 1. Early arthritis clinics are available in 77% of departments, which is an improvement on the previous year but still suboptimal.
- 2. The NEIAA has driven significant improvements in rheumatology services but still only 47% of people were referred within three days (vs 41% in Year 1).
- 3. First specialist review was achieved within three weeks of referral for 48% (vs 38% in Year 1).
- 4. Delays in specialist review were greater for patients with a final diagnosis of axial spondyloarthritis compared to EIA.
- 5. Many patients referred ultimately did not have a diagnosis of EIA, with only 40% of referrals entering EIA follow-up pathways.
- 6. Treatment initiation was within six weeks of referral for 64% (vs 54% in Year 1).
- 7. The vast majority of patients received disease education and self-management support but there is ongoing variability in clinician- and patient-reported experience of this support.
- 8. Access to allied health professionals (AHP) remains incomplete, especially for mental health services (only available in 38% of providers).
- 9. Trusts/Health Boards are widely engaging with treat to target strategies, with a newly diagnosed patient receiving on average six appointments in the first 12 months from diagnosis.
- 10. Half of Trusts/Health Boards report provision of emergency access to advice for patients commencing treatment for EIA.
- 11. Annual review was reported to occur for only 48% of patients.
- 12. 12-month outcome data show that 52% of people were in disease remission one year after diagnosis.
- 13. Patient-reported outcome data confirm the significant impact of inflammatory arthritis in terms of mental health, physical function and work productivity. Clinically significant improvements were seen in all of these measures over the first 12 months of specialist care.
- 14. NEIAA reports now inform the Best Practice Tariff (BPT) that launched in 2019, providing three reports between launch and suspension of the BPT due to COVID-19.

# Key findings

# Provision of care



77%

of departments offer an early arthritis clinic



38%

of providers have access to psychology health professionals



50%

of providers have emergency access to advice for patients starting treatment for EIA

# Time to first appointment



47%

of patients were referred within three working days



48%

of patients referred with suspected early inflammatory arthritis were seen within three weeks

# Diagnoses of people eligible for follow-up



40%

of referrals entering EIA follow up pathways

### **Treatment**



64%

of patients with a diagnosis of early inflammatory arthritis were prescribed a conventional diseasemodifying anti-rheumatic drug (cDMARD) within six weeks of referral



6 appointments

Newly diagnosed patients receive on average six appointments in the first 12 months

# **Annual review**



48%

of patients who had 12-month clinical data returned received an annual review

# Disease remission



52%

of people were in disease remission 12 months after diagnosis

### Recommendations

#### Rheumatology services and providers

- 1. Improve early arthritis pathways, ensuring that they are accessible to referrers (key finding 1).
- 2. Evaluate local barriers to rapid specialist review (key finding 3), bridging data from the NEIAA and the Getting It Right First Time (GIRFT) initiative.
- 3. Explore mechanisms for improving and maintaining systems to support rapid but safe initiation and escalation of conventional disease-modifying anti-rheumatic drugs (DMARDs) (key finding 6).
- 4. Ensure access to all relevant specialist AHP services, including mental health services, is available in all Trusts/Health Boards and that individual need for these services is assessed (key finding 8).
- 5. Ensure that emergency access (within 24 hours) to advice is available for people with EIA (key finding 10).
- 6. Develop follow-up care pathways to increase the proportion of patients achieving remission within one year of diagnosis (key finding 12).
- 7. Develop and implement annual review processes (key finding 11).

#### Rheumatology services and service users

8. Work together to increase patient education and self-management support and reduce discrepancy in reported education provision across providers and patients (key finding 7).

#### Educators

- 9. Expand and promote GP education resources on the clinical features that should trigger referral and on the importance of appropriate and timely referral of patients with suspected EIA and axial SpA (key finding 2).
- 10. Promote training for musculoskeletal physiotherapy services and first contact practitioners in addition to training for other relevant specialties (gastroenterology, ophthalmology, dermatology) to increase early detection of axial SpA symptoms and prompt referral (key finding 4).
- 11. Further develop training aimed at improving mental health comorbidity detection and management in patients with EIA (key finding 13).

### Commissioners, funding bodies and Getting It Right First Time (GIRFT)

- 12. Continue to promote the Best Practice Tariff in England (key finding 14) and explore other incentives to drive service improvements.
- 13. Explore triage mechanisms to
  - a. reduce referrals for conditions more appropriately managed in primary care (key finding 5).
  - b. promote direct referrals from musculoskeletal (MSK) physiotherapy services and first contact practitioners where appropriate (key finding 3 and 4).

### All involved in healthcare provision

14. Given the impact of the COVID-19 pandemic explore how remote services can be utilised to maintain and improve the care provided to patients with EIA (all key findings).

# Interpreting the NEIAA report

#### Trust/Health Board participation

All Trusts/Health Boards providing rheumatology care and seeing patients with suspected EIA were eligible to take part. Rheumatology outpatient activity data from NHS Digital and the NHS Wales Informatics Service enabled us to identify all eligible Trusts/Health Boards. The 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. The 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 the audit launched.

#### Case ascertainment

All patients aged 16 or over who were first seen in a specialist rheumatology service with suspected EIA between 8 May 2019 and 27 March 2020 were eligible. Data collection was suspended from March 2020 due to the COVID-19 pandemic. All results reported in this document are from this data collection period unless stated to the contrary. Currently we have no external method to assess case ascertainment, so there may be sampling bias. Given the better ongoing levels of recruitment, and the demographic similarities of the sample compared to other large EIA cohorts [5], we believe that any sampling bias is small and does not impact on the validity of the findings.

#### Data quality and completeness

To minimise issues relating to data entry errors and incompleteness, 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 region¹. 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 accompanying materials. This 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. These graphs also supply markers that delineate performance thresholds for Trusts/Health Boards that are outliers at 'alert' and 'alarm' (two and three standard deviations [SDs] from the national mean, respectively).

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.

<sup>1</sup>Regions defined by **BSR**.

#### Standards used

Care was assessed against **NICE Quality standard 33** for care of patients over the age of 16 with RA. Details of the standards of care can be found in Table 1. During the course of Year 2 data collection a **new version of NICE Quality standard 33** was published with a reduced number of statements. To allow reporting on changes in performance from Year 1 to Year 2, and in recognition of the importance of each of the previous quality statements, data relevant to these continue to be collected, analysed and reported on.

Table 1. Standar	rds 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 rheumatoid arthritis are offered conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within three months of onset of persistent symptoms.
Statement 4	People with rheumatoid arthritis are offered educational and self-management activities within one month of diagnosis.
Statement 5	People who have active rheumatoid arthritis 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 rheumatoid arthritis and disease flares or possible drug- related side effects receive advice within one working day of contacting the rheumatology service.
Statement 7	People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service.

The probability that a patient achieves QS 1 to QS 3 is 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. The empirical Bayes method is a statistical approach to account for differences in sample size between departments, allowing meaningful comparisons. Missing data are accounted for using multiple imputation. For QS 4 to QS 7, estimates are calculated using unadjusted logistic models.

#### 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 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 healthcare provider, or completion of paper forms which are entered online by the clinical team.

### Governance including patient involvement

The NEIAA has an independent Patient Panel, who have reviewed and supported 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 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. The policy is available www.ons.gov.uk/methodology/methodologytopicsandstatisticalconcepts/disclosurecontrol/healthstatistics.

### **Outlier policy**

The NEIAA outlier policy is available online at www.arthritisaudit.org.uk.

#### Outlier analysis during COVID-19 pandemic

The NEIAA has updated the approach to outliers in accordance with the interim HQIP guidance. In parallel with reopening the audit on a voluntary basis from August 2020, outliers at an alert (> two standard deviations from overall mean) and alarm level (> three standard deviations from overall mean) were contacted based upon their data available for the 2019/2020 year. The timelines for working with outlier departments published by HQIP were followed.

# Data quality

### **Estimating participation**

To find evidence of hospital engagement in the audit, and thereby potential for sampling bias in case ascertainment, recruitment numbers by provider are described.

#### Data completeness and missing data

Baseline records have been created for 13,578 patients. Information is provided on data completeness for each measure that is reported.

#### Data accuracy

Data collected for this audit are self-reported by Trusts/Health Boards. 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 online at **www.arthritisaudit.org.uk**.

# Headlines: Provision of care

### What are we measuring?

The number of consultants, trainees and specialist nurses, as well as availability of EIA services and access to AHP services, emergency care and to telephone advice lines.

#### **Definition and methods**

Organisational data were collected from each Trust/Health Board at the outset of the audit. Year 2 data entry was open from May 2019 until August 2019. Staffing ratios and access to AHP services can fluctuate over time, and this information is 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 expected numbers for clinical time only being included. Further clarification will be made available in help boxes and FAQs for future data collection.

#### What did we find?

We received data for 2019/2020 from 118/137 Trusts/Health Boards that provide outpatient rheumatology care. The national average WTE numbers of staff, departmental organisational factors, and access to AHP services are detailed in Table 2. The most striking change is an increase in availability in EIA clinics, which rose from 69% in 2018/2019 to 77% in 2019/2020. There were no significant changes in all other measures detailed in Table 2.

Table 2. Organisational data

Structural factor <sup>2</sup>	Finding
Consultants, mean (SD)	4.1 (2.0)
Training grade doctors, mean (SD)	1.3 (1.1)
SAS doctors, mean (SD)	0.4 (0.7)
Specialist nurses, mean (SD)	3.6 (1.8)
Physiotherapy access	110/118 (93%)
Podiatry access	90/118 (76%)
Occupational therapy access	112/118 (95%)
Psychology available in department	45/118 (38%)
EIA pathway used in department	89/118 (75%)
EIA clinics available in department	91/118 (77%)
Shared care agreements with primary care for drug monitoring	113/118 (96%)
Musculoskeletal ultrasound available	115/118 (98%)
Telephone advice line available to patients	115/118 (97%)
Emergency access to rheumatology advice (within 24 hours) available to patients	59/118 (50%)

 $<sup>^2\</sup>mbox{Staffing numbers represent WTE posts.}$ 

The organisational data reported 452 WTE consultants; average (mean) number of consultants and specialist nurses across all Trusts/Health Boards are shown in Figure 1.

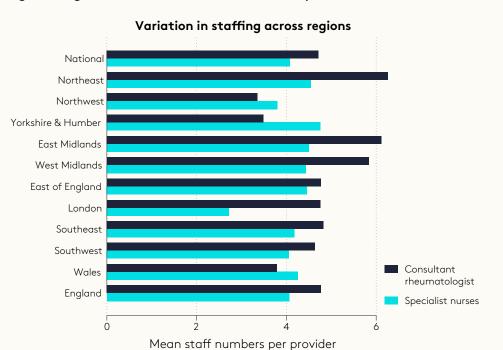


Figure 1. Regional staff numbers: consultants and specialist nurses

Integrated support for mental health is low, with fewer than half of Trusts/Health Boards reporting access to psychology services in their department. A small number of Trusts/Health Boards continue to report no access to important specialist AHP services.

#### 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.

NICE-recommended specialist AHP support is not universally available to patients. Access to mental health services in particular remains 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.

#### Why is this important?

Staffing and structural factors are linked to performance against the **NICE quality statements**. The increase in EIA clinic availability is important as this is one of the organisational factors that associates with rapid treatment for EIA patients; this is a finding that has been demonstrated consistently by the NEIAA.

Specialist AHP services are recommended by NICE in recognition of their importance in managing specific aspects of EIA. The lack of service availability in some Trusts/Health Boards means some patients are not able to receive optimal care.

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. The importance of support to patients via a telephone advice line (or alternative mechanism) is further discussed in the section on QS 6.

# 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 for suspected EIA.

#### **Definition and methods**

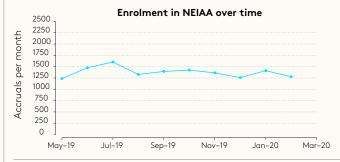
Patients were eligible for entry into the NEIAA if they were referred by their primary care physician (or another non-rheumatology healthcare professional) for assessment of a possible inflammatory musculoskeletal problem. This included both potential peripheral joint and spinal problems. Patient characteristics including age, gender, ethnicity and smoking status were supplied by clinicians.

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

#### What did we find?

A total of 13,578 patients with suspected inflammatory arthritis were seen in rheumatology services in England and Wales (Figure 2).

Figure 2. NEIAA 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). Socioeconomic position regional differences were similar to those observed in Year 1.

Table 3. Patient demographics.

Characteristic	Value
Mean age (SD)	55 (16)
Female	8,861/13,578 (65%)
White ethnicity	11,367/13,578 (84%)
Current smoker	2,312/13,578 (17%)

#### What does this mean?

The findings show 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 will enable commissioners and healthcare providers to evaluate the demands placed on their rheumatology services and linked workforce requirements. In addition, the audit supplies information on the demographics of patients that need to be cared for.

The demographic 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 referred with suspected EIA. For patients with a diagnosis of a new inflammatory arthritis, more 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 additional patient characteristics including autoantibody results and work status.

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

#### What did we find?

Data on diagnosis were provided for 12,653/13,578 (93%) of patients. RA was the most common diagnosis, accounting for 3,747 (30%) of patients with a recorded diagnosis. Psoriatic arthritis was the diagnosis in 1,050 (8%) and osteoarthritis was the confirmed diagnosis in 2,307 (18%) (see Table 4 for further detail).

Full diagnosis data were available for 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). Psoriatic arthritis was the second most common diagnosis.

Table 4. Diagnoses of patients referred to rheumatology services

Diagnosis	Number n = 12,653/13,578 with a recorded diagnosis
Rheumatoid arthritis	3,747 (30%)
Osteoarthritis	2,307 (18%)
Undifferentiated arthritis	1,199 (9%)
Psoriatic arthritis	1,050 (8%)
Fibromyalgia	489 (4%)
Crystal arthritis	464 (4%)
Reactive arthritis	346 (3%)
Axial spondyloarthritis	244 (2%)
Mechanical back pain	189 (1%)
Connective tissue disease	160 (1%)
Other	2,458 (19%)

Table 5. Diagnoses of patients with EIA eligible for follow-up

Diagnosis	Number
Rheumatoid arthritis	3,579 (71%)
Psoriatic arthritis	623 (12%)
Undifferentiated arthritis	555 (11%)
Axial spondyloarthritis	69 (1%)
Other	188 (4%)

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). Just under two-thirds of patients had positive autoantibodies.

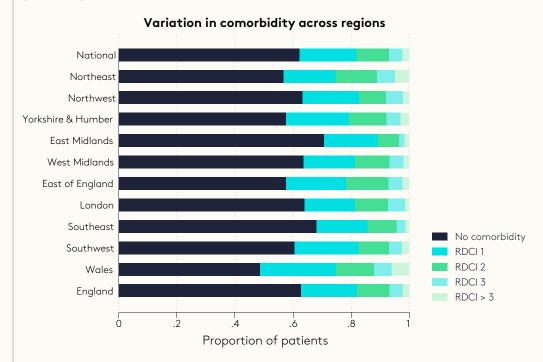
Table 6. Characteristics of patients with confirmed EIA

Characteristic	Value
Mean age (SD)	57 (16)
Female	3,071/5,014 (61%)
White ethnicity	4,314/5,014 (86%)
Current smoker	995/5,014 (20%)
Greater than 20 hrs work/week	2,355/4,913 (48%)
RhF or CCP positive	2,577/4,480 (58%)

 $\mathsf{CCP} = \mathsf{citrullinated} \; \mathsf{C-peptide}; \; \mathsf{RhF} = \mathsf{rheumatoid} \; \mathsf{factor}$ 

The comorbidity burden is low overall but varied amongst patients across geographic regions, with the highest number of patients with comorbidity in Wales (see Figure 3). This highlights the need for case mix adjustment as comorbidity may negatively affect the speed of treatment initiation.

Figure 3. Regional variation in comorbidity burden amongst patients with EIA (n = 5,014)



\*RDCI = Rheumatic Disease Comorbidity Index. The RDCI is a composite weighted comorbidity measure validated for use in RA epidemiological studies [5]

### What does this mean?

The proportion of patients recruited who have EIA is consistent with earlier NEIAA reporting. The spread of diagnoses is reflective of how difficult it can be to distinguish EIA from other conditions. The high proportion of EIA diagnoses reflects the effectiveness of triage services.

Whilst most patients do not have comorbidity at diagnosis, comorbidity varies across geographic regions. Many RA patients, at the time of diagnosis, have identifiable markers for less favourable outcomes.

### 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 linked quality improvement work. Providers who are referred more patients diagnosed with non-inflammatory conditions may have an opportunity to improve patient selection for EIA services.

An important message to all clinicians involved in assessing patients for possible EIA is that a significant proportion of patients will not have positive autoantibody tests.

Given the known impact of smoking status on RA it is important that support to stop smoking is available to patients when appropriate.

# Quality statement 1: GP referral delays

#### What are we measuring?

Whether patients with suspected EIA are referred to a specialist within the three working days recommended by NICE. This statement is a measure of primary care performance.

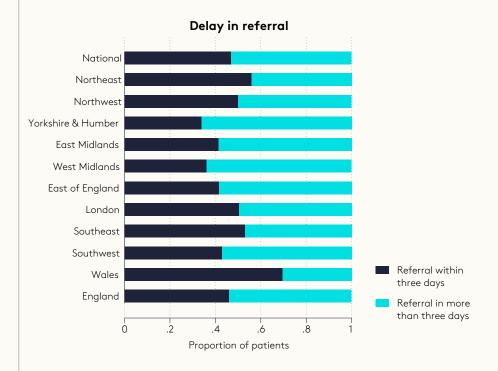
#### **Definition and methods**

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. Results are adjusted for case mix.

#### What did we find?

Information was provided to calculate QS 1 for 13,093/13,578 (96%) of patients. Nationally 6,178/13,093 (47%) of patients were referred within three working days (see Figure 4), an improvement of 6% on last year's performance. QS 1 attainment was highest in Wales, consistent with previous NCAREIA and NEIAA reports. Provider level performance, adjusted for case mix, are detailed in the accompanying tables.

Figure 4. QS 1 (GP referral within three days): attainment variation across the geographic regions (n = 13,093)



#### What does this mean?

Referrals from primary care are still not happening fast enough for most patients, and in particular for axial SpA patients (see later section on axial SpA results). Timelines to referral continue to vary widely across regions and Trusts/Health Boards. The NEIAA has seen a steady and sustained improvement in timely referral since its launch in May 2018.

### Why is this important?

Delays in referral from primary care are a key barrier to prompt treatment initiation. This measure evaluates the primary care contribution to delays in care. Findings serve as an indicator for where further education may be needed 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.

#### **Definition and methods**

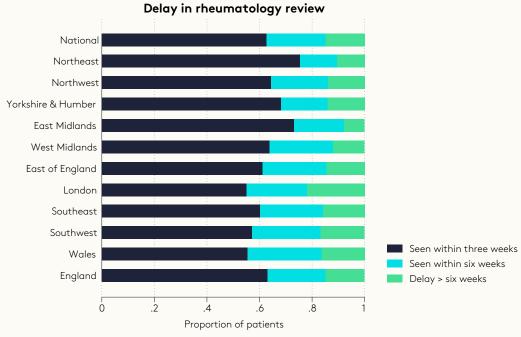
The number of patients seen within three weeks of receipt of referral is calculated against the total number of patients enrolled. Date of referral was defined as the date provided in response to: date referral letter received by Trust/Health Board and the date seen was defined as date of assessment in rheumatology clinic. Results are adjusted for case mix.

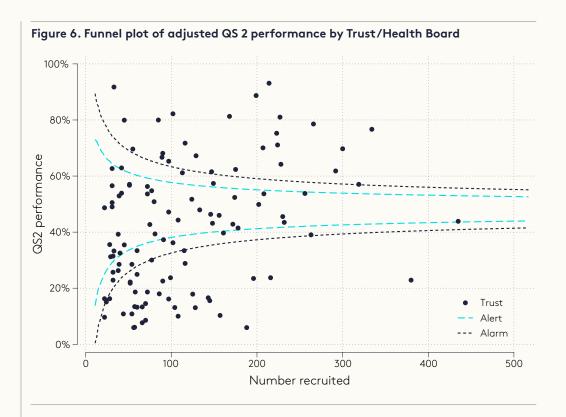
#### What did we find?

Information was supplied to calculate this statement for 13,301/13,578 (98%) of patients. Nationally 6,381/13,301 (48%) of patients referred with suspected EIA were seen within three weeks. This reflects an improvement of 10% compared with the last NEIAA report.

The average (median) assessment delay was 16 days (IQR 1-30), compared to 28 days (IQR 17-52) in the first annual report. Only 57 patients waited over six months for assessment, compared to 267 in the previous year. The stacked bar graph (Figure 5) shows the variation in waiting times across regions. Adjusted QS 2 performance is shown in the funnel plot (Figure 6).

Figure 5. Delay in rheumatology review by geographical region (n = 13,301)





Patients referred via an EIA pathway had an 83% increased odds of meeting QS 2 (odds ratio (OR) 1.83; 95% CI 1.69 to 1.98, P < 0.0001). This corresponds to 52% of patients meeting QS 2 who were referred via an EIA pathway, compared to 38% of patients not referred via an EIA pathway. QS 2 performance was statistically different by region, with the Northeast having the highest probability of QS 2 attainment.

A total of 49 Trusts/Health Boards had performance against this QS that was two SD below the national average ('alert' category); 33 had performance that was three SD below the national average ('alarm' category). These numbers were comparable to Year 1 (51 and 36 Trusts, respectively).

### What does this mean?

Rheumatology departments across England and Wales are seeing patients with suspected EIA more rapidly than in previous years. Substantial regional variation continues to exist, and provider-level reports will enable commissioners to find where there is greatest need for support.

### Why is this important?

Prompt review is a key facilitator of prompt diagnosis and treatment for EIA. Improvements since the NEIAA launched in 2018 reflect the rheumatology community's awareness of the importance of this metric.

# 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 the date that 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 statement.

Since the last NEIAA report the treatment time recommendation in the **NICE QS33 guideline** has been amended to read: "Adults with active rheumatoid arthritis start conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within six weeks of referral, with monthly monitoring until their treatment target is met." The NEIAA assesses treatment commencement in line with the updated guideline. This is also consistent with how QS 3 was measured in the first NEIAA annual report.

#### What did we find?

Out of the 5,014 patients eligible for EIA follow-up, 3,559 (71%) had information to calculate QS 3 achievement. Nationally 2,279/3,559 (64%) of patients with a diagnosis of EIA were established on a cDMARD within six weeks of referral, a 10% improvement on last year's performance.

The bar graph in Figure 7 shows regional variation in time to cDMARD initiation. The most striking improvements were seen in the Northeast of England, where the proportion of patients meeting QS 3 has increased by over 15% since the first NEIAA report. Trust/Health Board level variation in QS 3 performance is presented in the funnel plot (Figure 8).

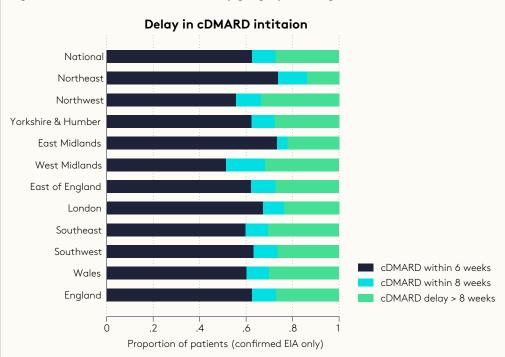


Figure 7. Time to cDMARD initiation by geographical region (n = 3,559)

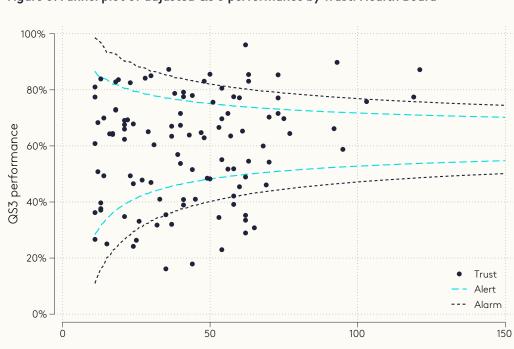


Figure 8. Funnel plot of adjusted QS 3 performance by Trust/Health Board

A total of 23 Trusts/Health Boards had performance against this QS that was two SD below the national average ('alert' category); 13 had performance that was three SD below the national average ('alarm' category).

### What does this mean?

There has been a clinically meaningful improvement in the proportion of people starting cDMARDs promptly after diagnosis. Substantial variation remains across England and Wales, although the number of Trusts/Health Boards performing significantly less well than the national average has reduced.

It is important to recognise that there are reasons, including patient choice and safety concerns, that could be impacting on failure to achieve this QS for some patients.

#### 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.

# 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.
- 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.

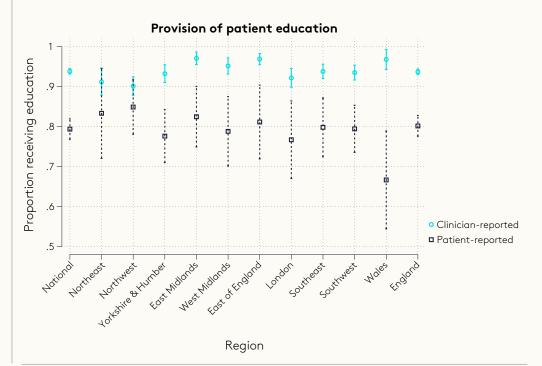
Patient-reported data are presented at national and regional level only, as too few patients responded to provide Trust/Health Board level data.

### What did we find?

Clinicians provided information to calculate this statement for 4,803/5,014 (96%) of patients eligible for EIA follow-up. Nationally 4,491/4,803 (94%) of patients with established EIA were offered timely access to education and information on self-management according to information provided from departments.

Feedback provided directly from patients was available in 671/5,014 (13%) of patients. Of these, 543/671 (81%) reported provision of education by three months. A regional breakdown is detailed in Figure 9. Adjusted Trust/Health Board QS 4 attainment is detailed in the accompanying tables.

Figure 9. QS 4 (provision of education): performance by geographical region (n = 4,803)



#### What does this mean?

Timely patient education is provided to most patients but importantly, is not provided to all.

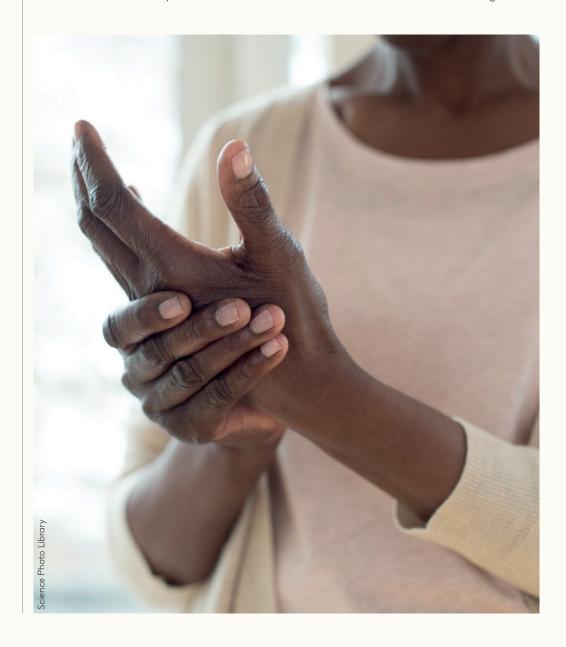
There is a discrepancy between education provision reported by departments compared to patients. Although the response rates were low from patients this discrepancy is more noticeable than in the previous annual report. The NEIAA data do not establish a reason for this.

### Why is this important?

Disease education and self-management training has been shown 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 education is likely to vary.

Specialist nursing and other AHP staffing ratios are factors likely to influence achievement of this QS and are worthy of review in Trusts/Health Boards where this QS is not being met.



# Quality statement 5: Treatment targets

#### What are we measuring?

Whether clinicians report that they agree a treatment target of low disease activity or remission with patients and offer regular review until targets are achieved.

#### **Definition and methods**

The number of patients with confirmed 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.

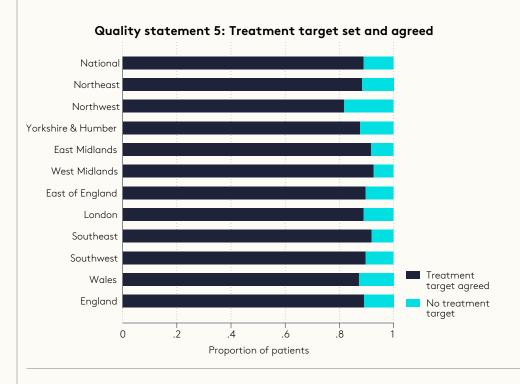
The number of appointments (face to face and/or telephone) attended by patients with a confirmed RA pattern EIA as recorded by clinicians three and 12 months after diagnosis.

#### What did we find?

Information on setting a treatment target was provided for 4,782/5,014 (95%) of patients. Nationally 4,257/4,782 (89%) of patients with confirmed EIA had a treatment target set and agreed (see Figure 10 for a regional breakdown).

The median number of appointments, including face to face and telephone, by three months of care was  $3 \, (IQR \, 2-4)$ , and by  $12 \, months \, was \, 6 \, (IQR \, 5-8)$ .

Figure 10. QS 5 (treatment target set and agreed): attainment by geographical region (n = 4,782)

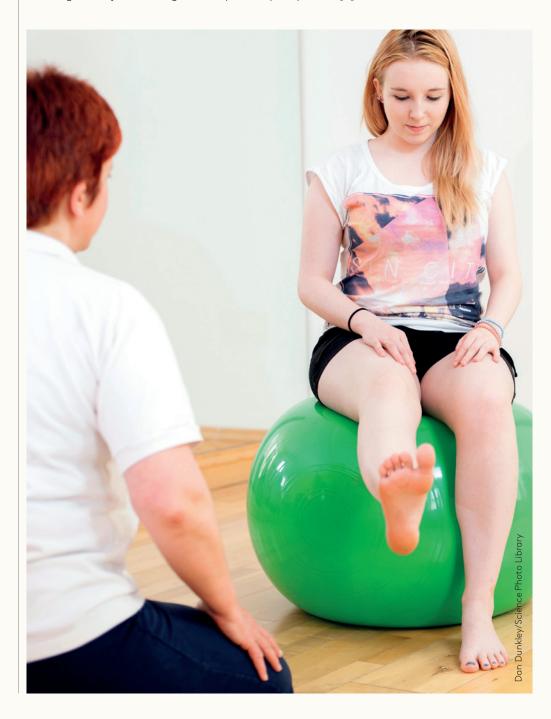


#### What does this mean?

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. Patients are, on average, being offered monthly appointments in their first three months of specialist care and ongoing regular appointments in their first year from diagnosis.

### 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. The number of appointments being reported also provides supportive evidence for a treat-to-target approach to care. 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 [6].



# Quality statement 6: Emergency access to care

#### What are we measuring?

Are patients provided with contact details for the department in case of a problem with their disease or treatment?

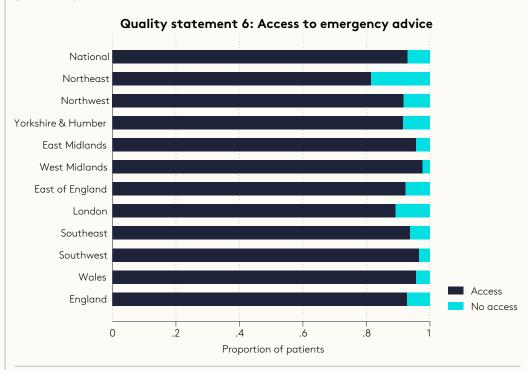
#### **Definition and methods**

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?

Information was provided to assess this QS for 4,790/5,014 (96%) of patients. Nationally 4,429/4,790 (92%) of patients were provided with access to rheumatology specialist advice (e.g. a telephone advice line) (see Figure 11 for the regional breakdown).

Figure 11. QS 6 (access to emergency advice): attainment by geographical region (n = 4,790)



#### 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 supplying advice, such as a dedicated email address or app.

#### 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 allows prompt intervention in the case of flare-ups of disease or complications from cDMARDs.

# Quality statement 7: Annual reviews

#### What are we measuring?

Have patients had an annual review 12 months after diagnosis? Additional information was gathered when an annual review had taken place.

#### **Definition and methods**

The number of patients with confirmed RA pattern EIA who have a 'YES' response to the question: has a formal annual review taken place?, against the total number of patients enrolled with EIA. Information was collected for individual patients via the clinician questionnaire 12 months after diagnosis. Clinicians were sent reminders at 12 months to let them know that the information was due. Information collected from patients recruited since the NEIAA inception (8 May 2018) are included (n = 12,815).

If an annual review had taken place, we asked whether three specific components were included: an assessment of bone health (e.g. Fracture Risk Assessment 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?

Information was missing for 3,825/6,457 (59%) patients recruited more than 12 months prior to the audit suspension due to COVID-19 in March 2020. In total, 2,632 patients had data returned on annual review status (see Table 1). Of these, 1,260 (48%) were reported to have received an annual review. This reflects a slight increase from 43% reported in Year 1. Regional variation in annual review completion ranged from 15% in London to 65% in the Northeast (see Figure 12).

Figure 12. Annual reviews

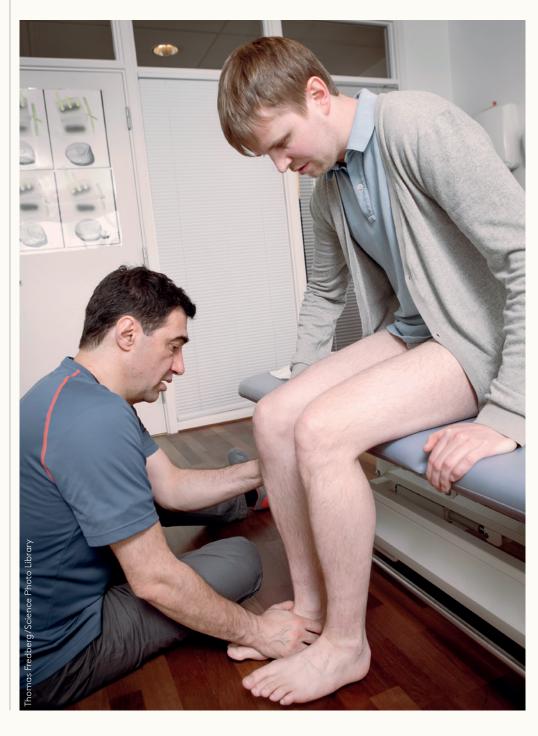


#### What does this mean?

Annual review is infrequently done for patients at the end of their first year of treatment for EIA, with huge variation in reported access across regions. Further work, beyond the remit of the NEIAA, is needed to understand what processes are in place/being implemented for annual review 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.



# Headlines: Treatment response

#### What are we measuring?

The disease activity of patients with rheumatoid pattern disease (Disease Activity Score (DAS28) at baseline and after three and 12 months of follow-up).

The proportion of people escalated to targeted therapies (e.g. biologics) by 12 months.

#### **Definition and methods**

DAS28 information was collected for individual patients eligible for EIA follow-up via a clinician questionnaire 12 months after diagnosis. Clinicians were sent reminders at 12 months to let them know that the information was due. Information collected from patients recruited since the NEIAA inception (8 May 2018) are included (n = 12,815).

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 2.6–3.2, moderate disease activity 3.2–5.1, and severe disease activity >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.

Clinicians provided information on whether or not targeted therapies had been started via a clinician questionnaire 12 months after diagnosis.

#### What did we find?

Baseline disease activity scores were available for 11,601/12,815 (91%) with a mean score of 4.6 (SD 1.5). Information was available to calculate 12-month disease activity outcomes for 2,748/12,815 (21%) patients with a mean score of 2.8 (SD 1.3). At 12 months, 1,429/2,748 (52%) patients were in a state of disease remission. The breakdown according to EULAR response is shown in Figure 13. Timely specialist review and rapid initiation of DMARDs were significant predictors of a good EULAR response: meeting QS 2 was associated with an odds ratio of 1.2 (95% CI 1.0 to 1.5) and meeting QS 3 associated with an odds ratio of 1.3 (95% CI 1.1 to 1.6) (see Figure 14(a) and (b)).

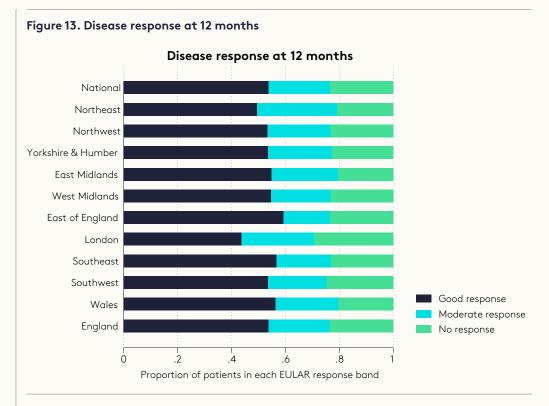
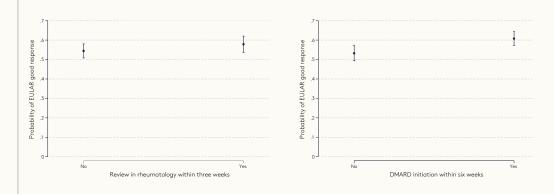


Figure 14. (a) and (b): Association between performance against QS 2 and QS 3 and clinical outcomes



### 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. Rapid rheumatology assessment and initiation of DMARDs are significant predictors of a good clinical response, reinforcing the evidence base that underpins the NEIAA. However, 1 in 5 people are in the EULAR 'no response' category at 12 months despite treatment. In addition, there was a high proportion of missing data at 12 months follow-up. The audit captures a 'snapshot' at specific time points from diagnosis and this needs to be taken into account when interpreting these results. However, the substantial regional variation suggests there may be major differences in outcome depending upon where a person is treated.

### 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; measuring both via the NEIAA will improve our understanding. Remission is a realistic target and if achieved and sustained will reduce the long-term impact of EIA.

## Headlines: Patient-reported outcomes

#### What are we measuring?

Patient-reported outcomes (PROs) capturing information on disease impact, functional impairment, mental health and work impacts.

#### **Definition and methods**

All patients eligible for EIA follow-up are invited to return PROs at baseline, three and 12 months. Patients could complete information either online via the patient portal or using printed questionnaires available in clinic from the rheumatology department. In the first year of the NEIAA, baseline PRO information was available for approximately 40% of eligible patients. To maximise the power of PRO data, information presented here (n = 12,185) reflects all available responses since the NEIAA inception (8 May 2018).

#### PRO data collected

Musculoskeletal Health Questionnaire (MSK-HQ): This is a 15-item questionnaire evaluating symptom impact. It is validated for use across several musculoskeletal health conditions. A score is calculated from the first 14 items and ranges from 0 to 56, with higher scores indicating better musculoskeletal 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 that are the standard screening tools recommended for use in the NHS to find people who have significant depression or anxiety. Each measure contains two items, with a score from 0 to 6. A score greater than two on either measure is considered a positive screen for 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 affects their performance at work. Overall impairment incorporates both absenteeism and presenteeism.

### What did we find?

PROs were available for 4,996/12,185 (41%) at baseline, 2,482/12,185 (20%) at three months, and 858/6,457 (13%) at 12 months. At baseline, patients reported a high impact of the disease, with significant levels of functional and work impairment, depression and anxiety. Improvement was seen across all domains, with changes consistently exceeding the minimum clinically important difference (MCID) for each measure (see Figure 15 for more detail).



#### What does this mean?

The substantial impact of inflammatory arthritis on patients, even in the early stages of their diagnosis, is clearly shown.

These data demonstrate the benefits of NHS care with improvements in all measures across England and Wales as a whole.

The burden of mental health comorbidity is large and highlights the need for access to psychological therapies.

The adverse impact on work is demonstrated. This is of substantial importance to individuals and their families but is also of public health importance, especially when considering presenteeism as well as absenteeism.

In interpreting these findings it is important to bear in mind the high proportion of missing data.

#### 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.

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.

Through this audit, the importance of mental health comorbidity is highlighted. 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.

## Headlines: Unplanned admissions

#### What are we measuring?

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

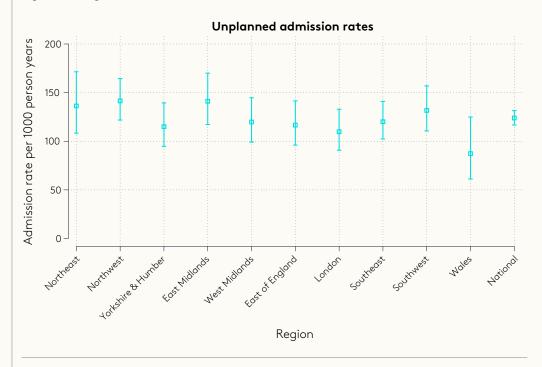
#### **Definition and methods**

All patients with a confirmed diagnosis of EIA, recruited since the NEIAA inception (May 2018) with a valid NHS number, were linked to NHS Digital and NWIS (n=12,185). The number of unplanned admissions (including attendances at emergency departments) were recorded. Event rates per 1000 patient-years were calculated. Cox proportional hazards models, adjusted for age, gender, ethnicity, smoking status, deprivation and comorbidity were used to describe associations with unplanned admissions.

#### What did we find?

In total, 1,077 patients had an unplanned admission in 8,692 patient-years of follow-up. The national unplanned admission rate was 123.9 per 1000 patient-years (95% CI 116.7 to 131.5), with rates ranging from 87 in Wales to 142 in the Northwest. The adjusted hazard ratio for admission did not differ significantly between any NHS Trust in England. The hazard ratio in Wales, compared to England, was 0.63 (95% CI 0.44 to 0.90).

Figure 16. Regional admission rates



### What does this mean?

Nationally, around 1 in 8 people receiving a diagnosis of EIA had an unplanned hospital admission within the first two years of diagnosis. Unplanned admissions are less likely in patients with newly diagnosed EIA in Wales compared to England (see Figure 16). Possible explanations include care quality, admission thresholds or unmeasured confounding.

#### Why is this important?

Unplanned admissions are a significant NHS burden and have substantial implications for patients. This information is especially relevant in times of finite NHS resources during the COVID-19 pandemic.

# Headlines: Joint replacements and mortality

## What are we measuring?

How often patients require joint replacement surgery and mortality rates within the first two years of diagnosis of EIA.

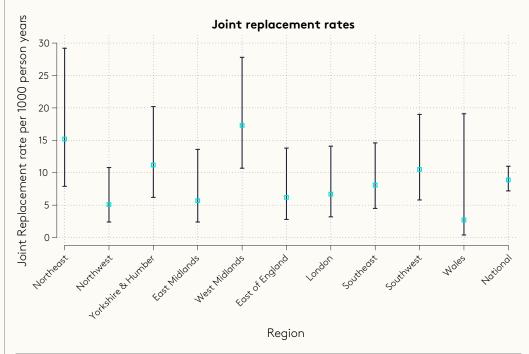
#### **Definition and methods**

All patients with a confirmed diagnosis of EIA, recruited since the NEIAA inception (May 2018) with a valid NHS number were linked to NHS Digital and NWIS (n=12,185). The number of joint replacements and deaths were recorded. Event rates per 1000 patient-years were calculated.

#### What did we find?

In total, 85 people had a joint replacement, corresponding to a rate of 8.9/1000 patient-years (95% Cl 7.2 to 11.0). The highest rate was observed in the West Midlands (see Figure 17).

Figure 17. Regional joint replacement rates



In total, 108 deaths occurred, corresponding to a mortality rate of 11.2/1000 patient years (95% CI 9.3 to 13.5). Mortality was highest in the Northwest, and lowest in London (see Figure 18). Adjusted statistical comparisons were not made between regions for joint replacements or mortality due to low numbers.

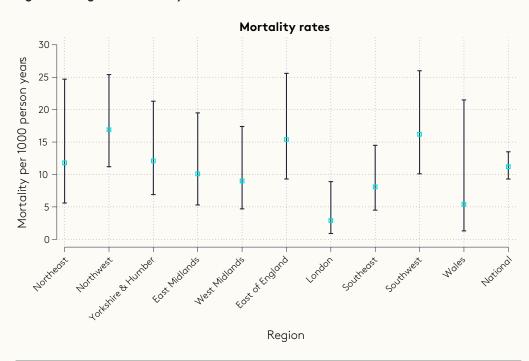


Figure 18. Regional mortality

Based upon the limited numbers of events accrued to date, there are too few numbers for the NEIAA to present Trust/Health Board level event rates for joint replacement and mortality (only one individual Trust/Health Board has had >five joint replacements, and none has had >five deaths).

#### What does this mean?

Very few deaths were recorded and very few people have joint replacements within the first two years of diagnosis. These findings would be expected given that mortality risks and joint damage such that replacement is required take time to accumulate. Information on mortality and joint replacements will become more valuable in future reports as follow-up data accrue.

## 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.

# Axial spondyloarthritis (axial SpA)

## What are we measuring?

Route of referral and delays in specialist assessment for suspected axial SpA.

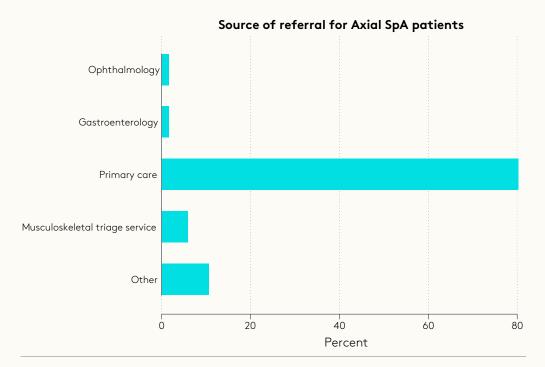
#### **Definition and methods**

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. The referral source was collected via the clinician baseline form.

#### What did we find?

In total 244/13,578 (2%) 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 19).

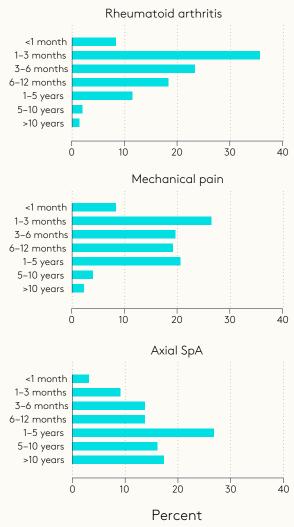
Figure 19. Source of referral for axial SpA patients



In contrast to both RA and mechanical back pain, the NEIAA data confirmed that patients with axial SpA tended to have substantially greater symptom duration prior to referral and specialist assessment (see Figure 20).

Figure 20. Comparison of symptom duration prior to specialist assessment in rheumatology

Symptom duration prior to assessment



Graphs by Working Diagnosis

#### What does this mean?

There continue to be major delays in diagnosing axial SpA. Axial SpA is a subtype of inflammatory arthritis that results in spinal inflammation and disability. Many 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. 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.

### Why is this important?

Axial SpA is a serious disease with substantial patient morbidity. NICE has published guidance on referral (NG65) [7] and 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 [8] in recognition of this.

Appropriate referral and prompt diagnosis have the potential to reduce the long-term impact of the disease and prevent spine and linked peripheral joint damage. These data are relevant to musculoskeletal physiotherapy services and first contact practitioners in addition to GPs and specialists in gastroenterology, ophthalmology and dermatology.

## Conclusions

Engagement with the NEIAA has continued to be high in its second year, with excellent recruitment despite the COVID-19 pandemic curtailing the data collection period.

The disease burden of inflammatory arthritis is high, but the audit provides evidence of substantial improvement in clinician- and patient-reported outcomes over the first 12 months of care in all regions of England and Wales.

This report incorporates long-term outcomes including mortality, joint replacements and unplanned admissions for the first time in the full annual report.

Performance against the **NICE standards** has improved since the last annual report, but is still 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 align 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

Non-mandatory NEIAA data collection resumed in August 2020 following suspension from late March 2020 due to the COVID-19 pandemic. The impact of the COVID-19 pandemic on the services Trusts and Health Boards can provide is likely to be substantial. The audit team plans to work with GIRFT to gain further insight into this and hopes that mandatory data collection on early arthritis care across the NHS will resume in the near future.

Since the outset, the audit team has sought to support those participating in the audit and changes are already being implemented to allow data capture from remote consultations. The audit team will continue to develop online tools to help units monitor their performance, webinars, quarterly newsletters and regular notifications to those at risk of being outliers.

The network of Regional Champions will continue to be utilised to support their local Trusts/ Health Boards and to gather and share information on quality improvement (QI) initiatives. The QI plan for the next year of the audit provides more detail on strategies for supporting NEIAA-related QI work. **See NEIAA QI 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 asterisk are more than three SDs below the mean.

Aneurin Bevan University Health Board\*

Ashford and St Peter's Hospitals NHS Foundation Trust\*

Barnsley Hospital NHS Foundation Trust

Basildon and Thurrock University Hospitals NHS Foundation Trust\*

Bolton NHS Foundation Trust\*

Bradford Teaching Hospitals NHS Foundation Trust

Brighton and Sussex University Hospitals NHS Trust\*

Cardiff and Vale University Health Board

Chesterfield Royal Hospital NHS Foundation Trust\*

Croydon Health Services NHS Trust\*

Cwm Taf Morgannwg University Health Board\*

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust\*

Dorset County Hospital NHS Foundation Trust\*

East Lancashire Hospitals NHS Trust\*

East Suffolk and North Essex NHS Foundation Trust\*

East Sussex Healthcare NHS Trust\*

Gloucestershire Hospitals NHS Foundation Trust\*

Guy's and St Thomas' NHS Foundation Trust\*

Hampshire Hospitals NHS Foundation Trust

Homerton University Hospital NHS Foundation Trust

James Paget University Hospitals NHS Foundation Trust\*

King's College Hospital NHS Foundation Trust\*

Leeds Teaching Hospitals NHS Trust\*

Manchester University NHS Foundation Trust\*

Medway NHS Foundation Trust\*

Mid Essex Hospital Services NHS Trust

North Bristol NHS Trust\*

North Middlesex University Hospital NHS Trust\*

North West Anglia NHS Foundation Trust

Northumbria Healthcare NHS Foundation Trust

Salford Royal NHS Foundation Trust\*

Salisbury NHS Foundation Trust

Southend University Hospital NHS Foundation Trust\*

Swansea Bay University Health Board\*

Tameside and Glossop Integrated Care NHS Foundation Trust

The Newcastle Upon Tyne Hospitals NHS Foundation Trust

The Princess Alexandra Hospital NHS Trust\*

The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust

The Rotherham NHS Foundation Trust

Torbay and South Devon NHS Foundation Trust\*

United Lincolnshire Hospitals NHS Trust\*

University Hospital Southampton NHS Foundation Trust\*

University Hospitals of Morecambe Bay NHS Foundation Trust\*

Warrington and Halton Hospitals NHS Foundation Trust

Whittington Health NHS Trust\*

Wirral University Teaching Hospital NHS Foundation Trust\*

Wrightington, Wigan and Leigh NHS Foundation Trust

Wye Valley NHS Trust

Yeovil District Hospital NHS Foundation Trust\*

## Appendix 2: Trusts/Health Boards with <6 patients entered

Airedale NHS Foundation Trust

Calderdale and Huddersfield NHS Foundation Trust

East Cheshire NHS Trust

Epsom and St Helier University Hospitals NHS Trust Gloucestershire Hospitals NHS Foundation Trust

Imperial College Healthcare NHS Trust Leeds Teaching Hospitals NHS Trust

North Tees and Hartlepool NHS Foundation Trust

Powys Teaching

Royal Free London NHS Foundation Trust

Royal Surrey County Hospital NHS Foundation Trust

Salisbury NHS Foundation Trust Stockport NHS Foundation Trust The Rotherham NHS Foundation Trust

Warrington and Halton Hospitals NHS Foundation Trust

West Hertfordshire Hospitals NHS Trust

## **Appendix 3: Non-participating Trusts**

County Durham and Darlington NHS Foundation Trust Queen Victoria Hospital NHS Foundation Trust Taunton and Somerset NHS Foundation Trust The Hillingdon Hospitals NHS Foundation Trust Western Sussex Hospitals NHS Foundation Trust

## Appendix 4: List of abbreviations

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 Healthcare 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

## Appendix 4: Glossary (continued)

PHQ4ADS Patient Health Questionnaire 4 Anxiety and Depression Screener

PRO Patient-Reported 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**

Ledingham Jo (Dr) (Chair) Lempp Heidi MacPhie Elizabeth (Dr) (Deputy Chair) McErlane Flora (Dr) Amlani-Hatcher Paul Norton Sam (Dr) Cramp Fiona (Prof) Oyebanjo Sarah Cripps Martin Pickles David Fairfax Rosie Sharp Charlotte (Dr)

Firth Jill (Dr) Stevens Roger

Gaffney Karl (Dr) Walker-Bone Karen (Prof)

Galloway James (Dr) Yates Mark (Dr)

Giles Ian (Dr)

## **Senior Governance Group**

Patel Sanjeev (Dr) (Chair, 2020-22) Kay Lesley (Dr) Price Elizabeth (Dr) (Chair, 2018-20) Lanyon Peter (Dr) Rivett Ali (Deputy Chair) Ledingham Jo (Dr) Cripps Martin Lempp Heidi

Ellis Benjamin (Dr) MacFarlane Gary (Prof) Fairfax Rosie MacPhie Elizabeth (Dr) Galloway James (Dr) Oyebanjo Sarah Hewitt Sasha Syed Ayas (Dr) Hoosain Tasneem Webb Dale (Dr)

Jacklin Clare

#### **Patient Panel**

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

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