British Society for Rheumatology

National Early Inflammatory Arthritis Audit

State of the Nation Summary Report 2024

Data Collection Period: 1 April 2023 – 31 March 2024

Geographic Coverage: England and Wales

Geographical Granularity: Countries, Integrated Care Boards, and Welsh Health Boards.

October 2024, amended March 2025

HQIP
Healthcare Quality Improvement Partnership

Contents

The National Early Inflammatory Arthritis Audit (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 and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes and, in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the NCAPOP, comprising around 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. **www.hqip.org.uk/national-programmes**.

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In line with the NHS commitment to paperless 2020, this report is only available in a digital format.

Further information about the content of this report can be found in the online **appendices**.

Introduction

Inflammatory arthritis, including rheumatoid arthritis (RA), is a significant disease burden in the UK, affecting over 400,000 people(1). Delays in treatment can lead to significant disability, reduced quality of life, and loss of productivity in the workforce(2)(3). Treatment delays for rare autoimmune rheumatic diseases (RAIRDs) such as systemic vasculitides are also associated with adverse outcomes including permanent disability(4).

The NEIAA aims to improve the quality of care for people living with rheumatic diseases by collecting demographic and care quality data on all eligible newly diagnosed patients over the age of 16 in rheumatology departments across England and Wales. Diagnoses required for enrolment in the audit include inflammatory arthritides, systemic vasculitides and connective tissue diseases:

Table 1 – Diagnoses eligible for recruitment to the NEIAA.

Eligible diagnoses		
Early inflammatory arthritis	**Connective tissue disease**	**Vasculitis**
Rheumatoid arthritis	Systemic lupus erythematosus	Giant cell arteritis
Psoriatic arthritis	Primary Sjögren's syndrome	Other large vessel vasculitides (not giant cell arteritis)
Axial spondyloarthritis	Systemic sclerosis	ANCA-associated vasculitis
Undifferentiated inflammatory arthritis	Idiopathic inflammatory myopathies	Other small/medium vessel vasculitides (ANCA-negative)
	Undifferentiated/other connective tissue disease or overlap syndrome	Behçet's syndrome

Data are collected over the first 12 months of care for all those recruited. These data assess waiting times, time to treatment, clinical response to treatment, and patient-reported outcomes.

Table 2 – Data collection requirements of the NEIAA.

Questionnaires		Rheumatoid-pattern EIA	Other EIA/ RAIRDs
Clinician-derived	Demographics and referral	✓	✓
	Diagnosis	✓	✓
	Clinical baseline (first visit)	✓	✗
	3-month follow-up	✓	✗
Patient-derived	Patient-reported outcome measures (PROMs) at baseline, 3, 6, 9 and 12 months after diagnosis	✓	✓

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The performance of individual healthcare providers is measured against the National Institute for Health and Care Excellence (NICE) **quality standard [QS33] 'rheumatoid arthritis in over 16s'**, last updated in 2020(5). Quality statement two (QS2) of this quality standard is used for outlier analysis, as described in our **outlier policy**. Outlier status is attributed to any unit whose performance against QS2 is three standard deviations or greater below the national mean. Units are also treated as an outlier if they recruit fewer than 11 patients into the audit.

Since the publication of our **2023 report**, there have been three important changes to the NEIAA.

1. The primary benchmarking metric changed to 'the time from referral to initiation of disease-modifying antirheumatic drugs (DMARDs) for those with rheumatoid-pattern EIA'. In previous years this metric was 'the time from referral to first rheumatology appointment'. This development reflects both the revised NICE guidance, and the strong research evidence base suggesting that prompt treatment of EIA improves patient outcomes(6)(7).

2. On 1 April 2023 NEIAA stopped recruiting cases of suspected EIA, and from then, only confirmed cases of all eligible conditions have been recruited.

3. In September 2023, NEIAA began collecting data at diagnosis for some RAIRDs. The diagnoses included are common enough to enable meaningful analysis and include the important rheumatic diseases that can cause acute morbidity and mortality. The aim of this additional data collection is to measure the time from referral to assessment by rheumatology departments, and the length of symptoms prior to referral, thereby monitoring whether people living with RAIRDs are disadvantaged compared to those with inflammatory arthritis. This change was introduced at the request of the audit's funders.

In addition to annual reports, we also provide rheumatology departments with near-real time data on key NEIAA metrics, facilitating local and national quality improvement (QI) initiatives. Further resources to support these processes can be found on our **QI resources webpage**, including data analysis tools, case studies, video guides and template documents such as driver diagrams.

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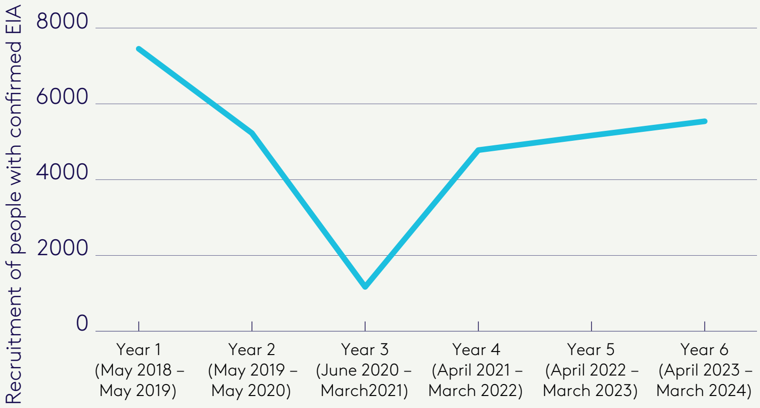
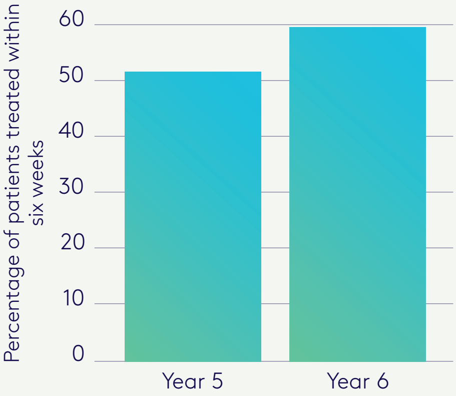
National Early Inflammatory Arthritis Audit
State of the Nation Summary Report 2024 Infographic

Recruitment rates continue to improve post-pandemic

86% of eligible units entered some data in year six.



Treatment timeliness for early inflammatory arthritis has improved

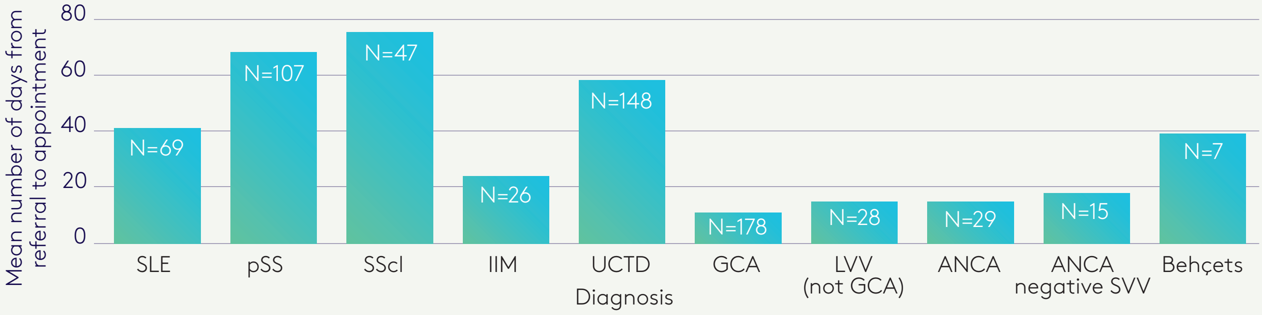


Most early inflammatory arthritis patients report that their symptoms significantly impact their employment

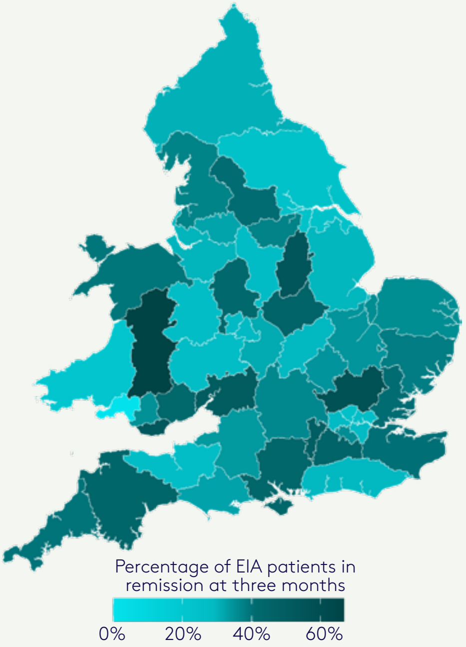
75% of those who were unemployed at diagnosis said this was due to their arthritis

20% of those who were employed at diagnosis said they had to change their work after diagnosis

Waiting times for Rare Autoimmune Rheumatic Diseases are highly variable (see list of diagnoses)



Remission rates remain stable at 35% but geographic variation persists



Recommendations

1 **Ensure consultant job plan guidance includes allocated time for triage and pre-referral specialist advice.**

2 **Ensure commissioned rheumatology services include protected EIA clinics.**

3 **Produce a national guideline recommending that people living with EIA are offered a DMARD on the day of their diagnosis.**

4 **Improve regulatory oversight of individual healthcare providers by utilising routine NEIAA data to assess standards of care and ensure compliance with quality standards.**

5 **Improve timely access to employment and mental health support programmes for people living with EIA.**

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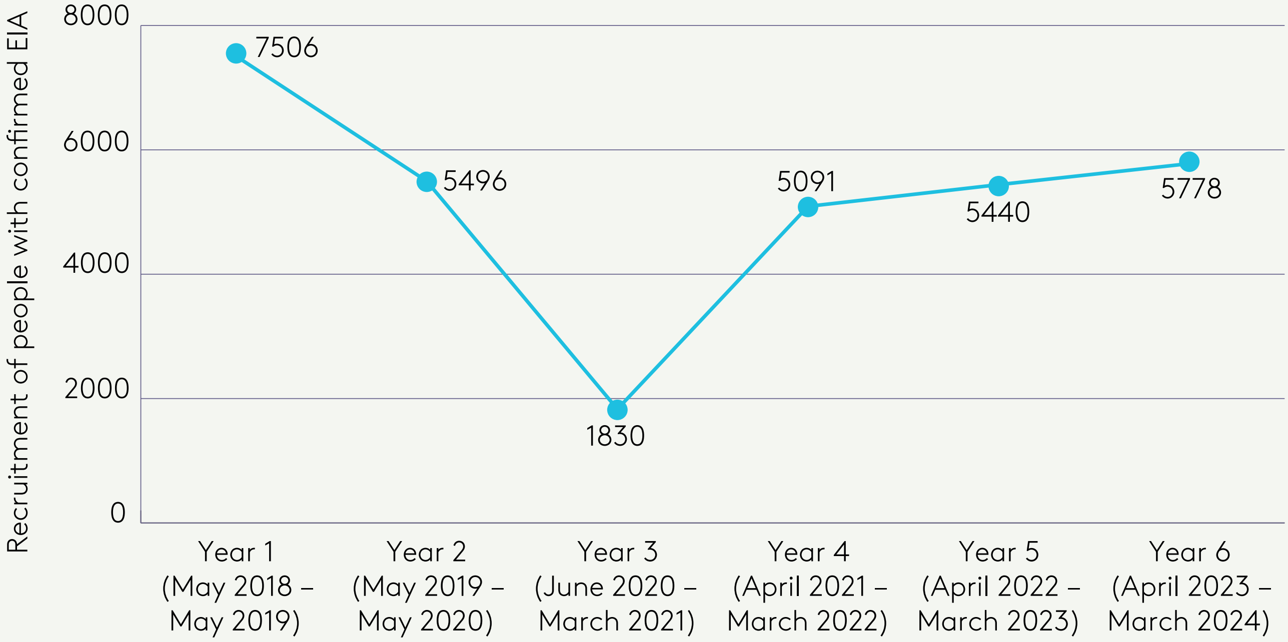
Recruitment and demographics

Key message 1

Increased engagement and data capture

Engagement with the NEIAA project is more widespread than ever, with 86% of eligible units returning data since our last report, an increase from 82%. The number of people presenting with EIA captured in the audit annually has increased since year three. However, it is important to acknowledge that many cases are still not captured. While no exact figures exist for the number of new cases of inflammatory arthritis in England and Wales per year, extrapolation from recent epidemiological studies suggests the true incidence of rheumatoid arthritis in these nations is likely greater than 20,000 per annum[8,9]. This suggests that NEIAA captures approximately one third of the cases eligible for enrolment.

Figure 1 – Recruitment of people living with confirmed EIA by year.



Demographics of people living with EIA

The demographic data of those included in the audit, and living with EIA, across the different diagnoses reflects the known epidemiology of the diseases, as described below for RA, psoriatic arthritis (PsA) and axial spondyloarthritis (AxSpA). The data highlight that EIA affects a diverse population with significant variations in age, gender, ethnicity, and employment status.

Gender distribution: People living with RA are predominantly female (63.5%). Conversely, a smaller proportion of those diagnosed with PsA (55.1%) and AxSpA (42.8%) are female.

Age distribution: The majority of people living with RA are aged 40–64 (46.7%). People living with PsA and AxSpA are notably younger, with a significant proportion in the 25–39 age range (28.3% and 45.5% respectively). In the general population of England and Wales, 20.2% are aged 20–39, and 32.1% are aged 40–64[10].

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Ethnicity: The majority of people across all EIA diagnoses are White, with percentages ranging from 78.9% to 86.6%. This broadly reflects the demography of England and Wales, where 81.7% of the population are White(11). Other ethnicities were less common, yet present across all EIA diagnoses, with the proportion of Asian people ranging from 7.3% to 12.0%, the proportion of Black people ranging from 0.9% to 2.8%, and those of other ethnic groups ranging from 3.2 to 6.0%.

Employment status: Compared to RA (44.7%), people living with PsA and AxSpA are more likely to be in paid work of >20 hours per week (64.7% and 73.8%, respectively).

Table 3 – Quality metric performance for patients referred with EIA.

Metric (Target)		Year 5	Year 6
GP referral within 3 days (NICE QS33* 2020; QS1**)	Percentage of patients meeting target	56%	51%
	Average delay between GP assessment and referral	19 days	21 days
Rheumatology appointment within 3 weeks	Percentage of patients meeting target	39%	44%
	Average wait time for specialist rheumatology appointment	31 days	31 days
Start DMARD within 6 weeks (NICE QS33* 2020; QS2***)	Percentage of patients meeting target	52%	60%
	Average time from referral to treatment	57 days	54 days
Remission by 3 months	Percentage of patients in remission by 3 months	35%	35%

	Years 1 – 6
PROMs headline	50% employed at diagnosis. Of those not in employment, 66% attributed this to their symptoms. Of those in work, 20% had had to change their role or hours due to their symptoms.

***QS33: NICE Quality Standard 33: Rheumatoid arthritis in over 16s**
****Quality Statement 1**
*****Quality Statement 2**

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Stakeholder engagement and patient-reported outcomes

Stakeholder engagement is a critical component of QI methodology. Through the involvement of key stakeholders, including patients, healthcare professionals and administrative staff, we can gain a better insight into the factors that influence healthcare delivery and outcomes. In 2023, we increased the proportion of data collected directly from patients and have used this to understand the mental health and employment status of individuals presenting with EIA and RAIRDs.

Since our **2023 report**, the NEIAA team have systematically monitored departmental engagement and performance in real-time, allowing for prompt and tailored support for struggling departments. The NEIAA Clinical Lead conducted interviews with departments throughout the year to identify specific issues and challenges, providing valuable qualitative data to highlight key areas for improvement.

The key themes that emerged from these interviews included:

Unit engagement from senior leadership: Engagement from senior leadership in rheumatology departments was essential for success. Units with low engagement often expressed that contributing data to the audit was not the best use of their department's time, or did not value the role of national audit. This lack of engagement hindered their participation and performance in the audit.

Staffing levels: Adequate staffing, both from consultants and nurses, was crucial. Under-resourced departments or those relying heavily on temporary or locum staff often struggled to perform well. Consistent, permanent staff were more likely to engage fully and contribute effectively to the audit.

Pathway management: Departments with non-specialist triage services often found that patients were signposted to an incorrect clinic. Several case studies during the year highlighted that rheumatology multidisciplinary team led triage dramatically improved performance. This change reduced bottlenecks and ensured more appropriate and timely referrals.

DMARD initiation: Variability in DMARD initiation practices was a significant issue. Some hospitals relied on GPs in the community to start DMARDs, while others referred people living with EIA to nurse-led clinics. Both methods had the potential to introduce significant delays, often extending waiting times by several weeks due to capacity bottlenecks.

Impact of stakeholder engagement

The stakeholder engagement activities conducted throughout the year demonstrated that even departments initially resistant to participation could be reached and motivated to contribute data. The increase in engagement from eligible units this year and the increase in recruitment of eligible cases, despite change to the audit's data collection requirements, are directly attributable to these systematic and targeted stakeholder engagement efforts, alongside the instrumental work of the Getting it Right First Time programme

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Early inflammatory arthritis pathways and treatment timeliness

The value of EIA pathways

In year six (1 April 2023 – 31 March 2024), 73% of confirmed cases were referred through an EIA pathway. Referral via an EIA pathway was associated with a much higher likelihood of being treated within six weeks compared to those referred via standard outpatient referral pathways or other routes*. Units with a documented EIA pathway and protected EIA clinics were more likely to meet quality standards(12). This highlights the importance of correct triage to ensure patients are directed appropriately to maximise timely treatment.

Table 4 – Treatment timeliness performance by pathway.

Referral route	Treatment <6 weeks	95% CI
EIA pathway	62%	61 to 63%
Any other route	42%	41 to 43%

Recommendation 1

Royal College of Physicians:
Ensure consultant job plan guidance includes allocated time for triage and pre-referral specialist advice.

Recommendation 2

Integrated Care Boards and Welsh Health Boards:
Ensure commissioned rheumatology services include protected EIA clinics.

Key message 2

Improved treatment timeliness

The key metric used for measuring care quality and determining outlier status is the proportion of people living with EIA who start DMARD therapy within six weeks of referral, as described in our **outlier policy**. The proportion of eligible patients treated within this timeframe was 8% higher than reported in year five.

Figure 2 – Percentage of patients treated within six weeks in years five and six.

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*(odds ratio 2.2; 95% confidence interval [CI] 2.1-2.4; p value <0.001)

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Figure 3 – Average time in days to treatment for EIA patients between years one and six.

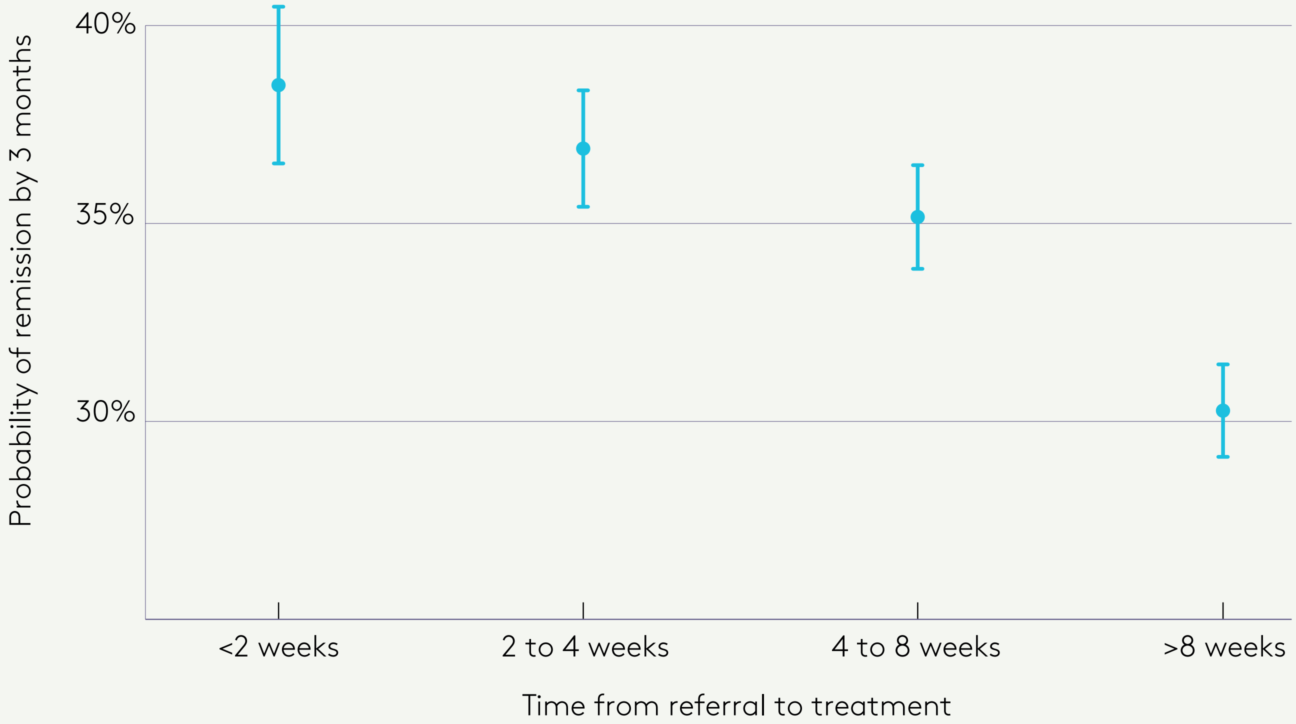
Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
54 days	47 days	48 days	56 days	57 days	54 days

Average time to treatment improved between years one and three. While this decreased in years four and five, performance has been maintained to pre-pandemic levels despite service and workforce pressures.

The clinical implications of delayed treatment

Research has previously shown that early intervention improves outcomes. NEIAA data support this, highlighting that, as time passes between referral and treatment initiation, the chance of early remission declines. Figure 4 below shows that the probability of achieving remission within three months of diagnosis is highest (almost 40%) when treatment is initiated within two weeks of referral and decreases significantly as the time to treatment increases. People living with EIA whose treatment is delayed by more than eight weeks have the lowest probability of remission (around 30%).

Figure 4 – Relationship between remission rates and treatment timeliness across all six years of NEIAA.



Adjusted for age, gender and disease severity at presentation

Recommendation 3

British Society for Rheumatology:

Produce a national guideline recommending that people living with EIA are offered a DMARD on the day of their diagnosis.

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Remission and geographic variation

Key message 3

Stable remission rates with geographic variation

Remission rates within 12 weeks of treatment remain stable at 35%, when compared to all five previous years of NEIAA. However, geographic variation in remission rates persists (see figure 5), highlighting the need for improved oversight of individual healthcare providers to ensure consistent compliance with quality standards. There was also geographic variation in the proportion of patients receiving treatment within six weeks (see figure 6).

Recommendation 4

Care Quality Commission and Health Inspectorate Wales:
Improve regulatory oversight of individual healthcare providers by utilising routine NEIAA data to assess standards of care and ensure compliance with quality standards.

Figure 5 – Percentage of EIA patients in year six achieving remission by three months, by Integrated Care Board and Welsh Health Board.

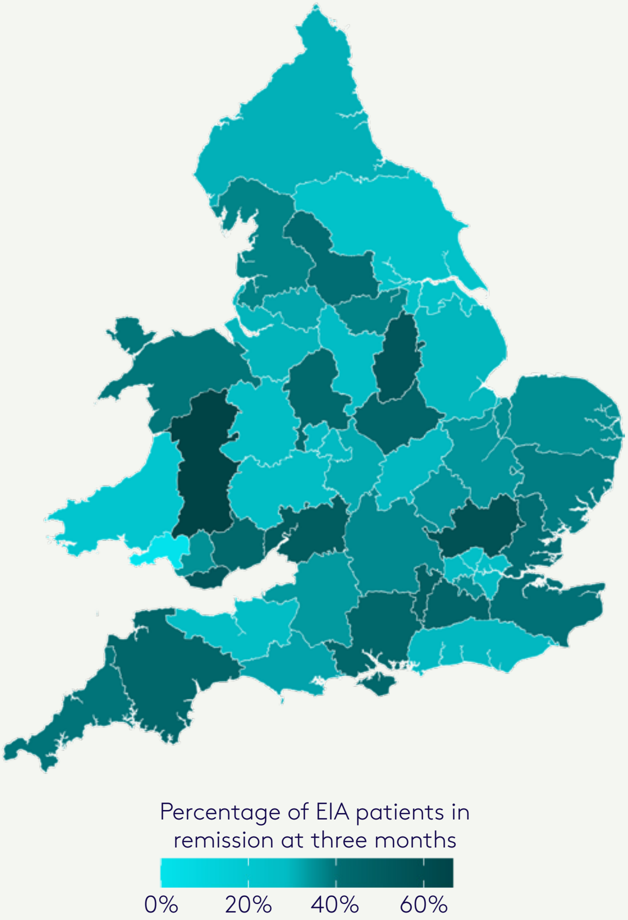
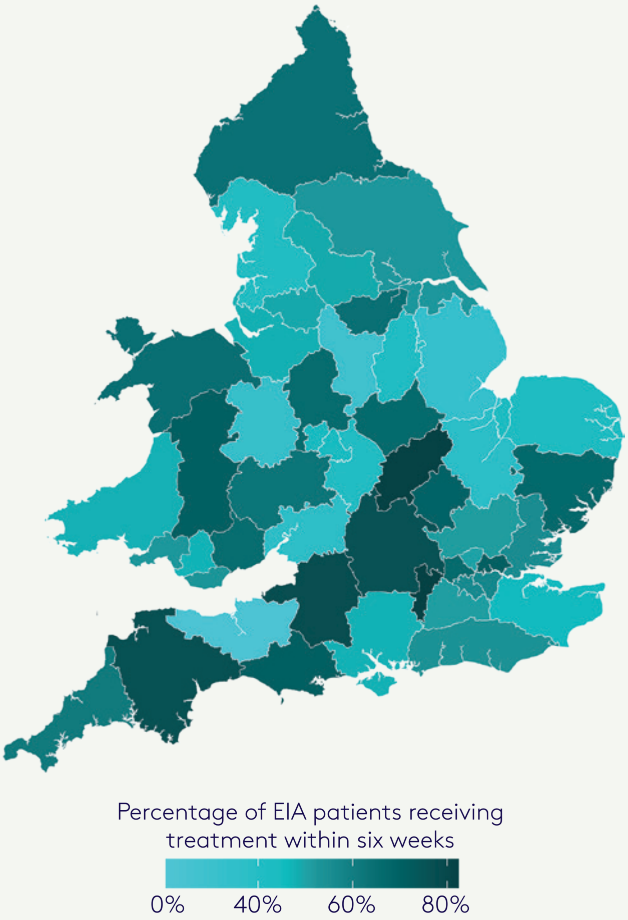


Figure 6 – Percentage of EIA patients in year six receiving treatment within six weeks, by Integrated Care Board and Welsh Health Board.



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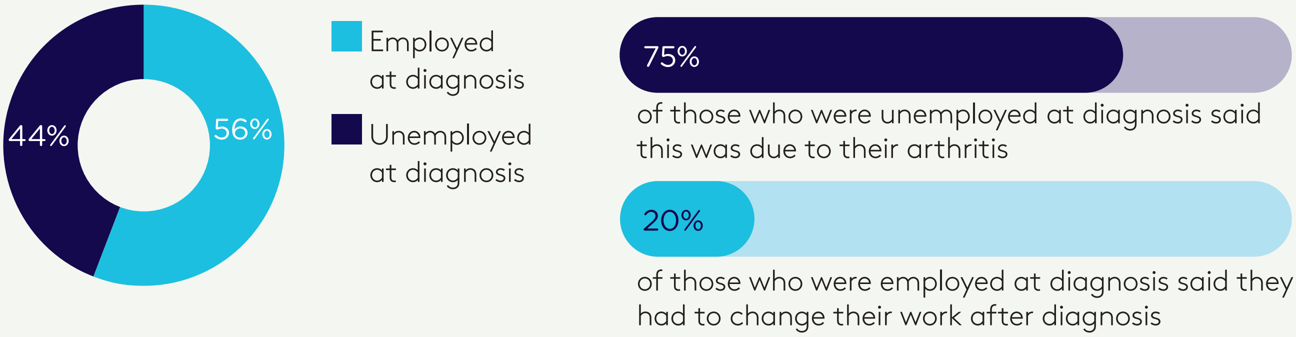
Employment and mental health

Key message 4

Burden of EIA on quality of life and employment

PROMs data confirm the significant burden of EIA symptoms on patients' quality of life and employment. The majority of people living with EIA are of working age, and a very high proportion report serious impacts of the disease on their contribution to the workforce.

Figure 7 – Impact of EIA on employment in year six.



75% of those who were unemployed at diagnosis said this was due to their arthritis

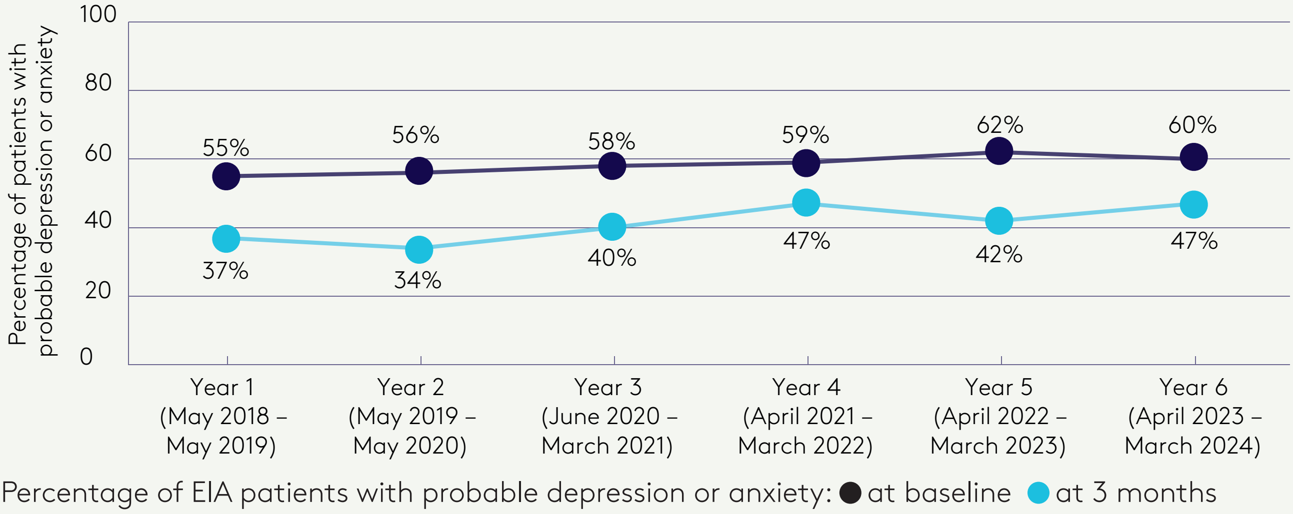
20% of those who were employed at diagnosis said they had to change their work after diagnosis

Key message 5

Rising mental health concerns

There has been an increase in patient-reported mental health symptoms, continuing a trend over the last six years. A majority of patients at presentation report mental health assessment scores which indicate symptoms of major depression or anxiety. While the burden of mental health symptoms appears to decrease between baseline and three months across all years, since year four this improvement has been less marked.

Figure 8 – Percentage of patients at baseline and three months with mental health assessment scores indicating symptoms of major depression or anxiety, by year.



Recommendation 5

Department for Works and Pensions, Department of Health and Social Care, NHS England and Welsh Health Boards:
Improve timely access to employment and mental health support programmes for people living with EIA.

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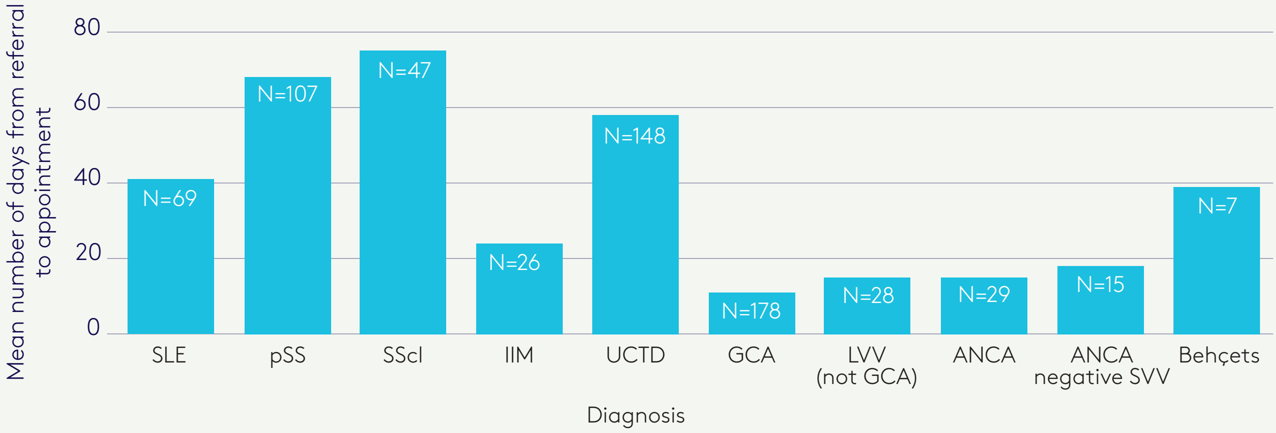
Rare autoimmune rheumatic disease diagnoses

Key message 6

Variable waiting times for RAIRD diagnoses

Since recruitment of the RAIRD diagnoses began, patients have been recruited for every diagnosis. Waiting times for the RAIRD diagnoses are highly variable. People living with rare rheumatic diseases with a high clinical urgency (e.g. vasculitis) have shorter waiting times, on average. Those living with other rare rheumatic diseases (e.g. Sjögren's syndrome and scleroderma) are waiting longer for diagnosis. This report provides the first-ever national benchmarking for these diseases in England and Wales.

Figure 9 – Waiting times for patients with RAIRD diagnoses recruited since September 2023.



Diagnosis	
SLE	Systemic lupus erythematosus
pSS	Primary Sjögren's syndrome
SScl	Systemic sclerosis
IIM	Idiopathic inflammatory myopathies
UCTD	Undifferentiated/other connective tissue disease or overlap syndrome
GCA	Giant cell arteritis
LVV (not GCA)	Large vessel vasculitides (not giant cell arteritis)
ANCA	ANCA-associated vasculitis
ANCA negative SVV	Other small/medium vessel vasculitides (ANCA-negative)
Behçets	Behçet's syndrome

Conclusion

Since our previous report, recruitment and treatment timeliness have improved. However, remission rates remain stable, and EIA symptoms continue to significantly impact mental health and employment. Our five recommendations aim to enhance the quality of care for people living with EIA, reduce variation in care provision and outcomes, and ensure compliance with quality standards.

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