

**Patient and clinician reported outcomes for patients with new presentation of inflammatory arthritis: observations from the National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis**

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## **Abstract**

**Objectives.** Our aim was to conduct a national audit assessing the impact and experience of early management of inflammatory arthritis by English and Welsh rheumatology units. The audit enables rheumatology services to measure for the first time their performance, patient outcomes and experience, benchmarked to regional and national comparators.

**Methods.** All individuals >16 years of age presenting to English and Welsh rheumatology services with suspected new-onset inflammatory arthritis were included in the audit. Clinician- and patient-derived outcome and patient-reported experience measures were collected.

**Results.** Data are presented for the 6354 patients recruited from 1 February 2014 to 31 January 2015. Ninety-seven per cent of English and Welsh trusts participated. At the first specialist assessment, the 28-joint DAS (DAS28) was calculated for 2659 (91%) RA patients [mean DAS28 was 5.0 and mean Rheumatoid Arthritis Impact of Disease (RAID) score was 5.6]. After 3 months of specialist care, the mean DAS28 was 3.5 and slightly >60% achieved a meaningful DAS28 reduction. The average RAID score and reduction in RAID score were 3.6 and 2.4, respectively. Of the working patients ages 16–65 years providing data, 7, 5, 16 and 37% reported that they were unable to work, needed frequent time off work, occasionally and rarely needed time off work due to their arthritis, respectively; only 42% reported being asked about their work. Seventy-eight per cent of RA patients providing data agreed with the statement 'Overall in the last 3 months I have had a good experience of care for my arthritis'; <2% disagreed.

**Conclusion.** This audit demonstrates that most RA patients have severe disease at the time of presentation to rheumatology services and that a significant number continue to have high disease activity after 3 months of specialist care. There is a clear need for the National Health Service to develop better systems for capturing, coding and integrating information from outpatient clinics, including measures of patient experience and outcome and measures of ability to work.

## **Introduction**

In 2009, the UK National Audit Office reported the cost-effectiveness of early aggressive treatment of RA but also significant geographical variation in RA care across the UK [1]. The UK National Institute for Health and Care Excellence 2009 clinical guidance (CG79) [2] and 2013 quality standards (QS33) [3] for the treatment of RA have emphasized the importance of the early diagnosis and treatment of RA.

In February 2014, the British Society for Rheumatology, with its information technology (IT) partner Northgate Public Services, launched a Healthcare Quality Improvement Partnership (HQIP)-funded national clinical audit of the management of early inflammatory arthritis (EIA).

The audit aims to assess the early management of patients referred to English and Welsh rheumatology units with suspected inflammatory arthritis and to enable patients to provide feedback on the services provided to them and on the impact of their arthritis on their daily lives. The ability to work has been demonstrated to be highly important to individual's health and welfare and to the wider economy, so this was also assessed within the audit [4]. The audit enables rheumatology services to measure for the first time their performance and patient outcomes and experiences benchmarked to regional and national comparators.

## **Methods**

The data collection tools were developed by the audit project working group and approved for use by HQIP and the National Health Service (NHS) Review of Central Returns, now called the Burden Advice and Assessment Service. There was a pilot of the questionnaires and web-based IT tool prior to the audit launch in February 2014. Patient consent, using HQIP- and Review of Central Returns-approved processes, was obtained at baseline and recorded for all analysed data. Ethical approval was not required, as this was an audit.

All individuals >16 years of age presenting to specialist rheumatology services in England and Wales with new-onset peripheral joint polyarthritis were included in the audit. Patients were included if they had RA, PsA, peripheral arthritis linked with SpA (not pure axial SpA) and undifferentiated arthritis, but were excluded if they had crystal arthritis or arthritis caused by infection (viral or septic arthritis) or linked with connective tissue disorders/vasculitis.

Clinician-derived 28-joint DAS (DAS28) scores [5] were recorded when assessed at appointments, at baseline and during up to 3 months of specialist review for patients with an RA pattern of disease [defined by the presence of polyarticular disease (more than five joints involved) or pauci-articular disease with positive CCP antibodies]. Follow-up data capture was for RA patients only, given the quality standards being assessed are for RA.

Patient-reported outcome and experience measures (PROMs and PREMs) and information on ability to work were also collected. The PROM used was the Rheumatoid Arthritis Impact of Disease (RAID) score [6], a validated tool for RA patients. The RAID score is a patient-derived composite measure of the impact of RA, assessing pain, functional capacity, fatigue, physical and emotional well-being, quality of sleep and coping. The overall score ranges from 0 (best) to 10 (worst). PROM data were collected for all patients at presentation and after 3 months of specialist review for RA patients. Prior to this audit's launch there were no established tools for assessing

work status in patients with inflammatory arthritis. Following consultation with experts in the field and with patient representatives, a short questionnaire was developed, agreed upon and piloted and was completed as part of the patient follow-up questionnaire. Impact on a patient's ability to work is presented for patients of working age, that is, 16–65 years.

The PREM used was an adaptation for use at 3 months of the tool developed by the Commissioning for Quality in Rheumatoid Arthritis group with the UK National Rheumatoid Arthritis Society for patients with RA [7]. To ensure confidential feedback, PREM data were collected after 3 months of specialist review via individuals not involved in the patient's care. The processes adopted were necessarily individual-to-individual trusts and, in general, were provided by non-clinical audit staff. The PREM statement analysed for this report was 'Overall in the past 3 months I have had a good experience of care for my arthritis', with responses categorised as agree (agree or strongly agree), neither agree nor disagree, disagree (disagree or strongly disagree) and not answered. Individual trusts have access to the full questionnaire responses. Translators required for any consultations were available to assist patients with their questionnaires.

Achievement of the seven National Institute for Health and Care Excellence quality standards [3] and information on key factors potentially impacting on patient experience and outcomes (catchment population, numbers of whole time equivalent consultants and specialist staff, availability of EIA clinics) were also assessed and are reported separately [8].

The Medical Research Council Lifecourse Epidemiology Unit in Southampton analysed the data. Further details on the methodology are provided as supplementary data, available at *Rheumatology* Online.

## **Results**

Data are presented for patients recruited from 1 February 2014 to 31 January 2015. One hundred and forty-three of 148 eligible NHS rheumatology providers in England and Wales registered to participate in the audit and 94% of these supplied data. Data from 6354 patients were analysed, representing >40% of expected incident RA cases.

Details of the patient demographics, diagnoses and departmental staffing levels per head of population are presented elsewhere [8]. Patients were predominantly women (66%) and 70% were of working age (16–65 years). The majority of patients recruited were of white British origin (79%), but there was significant geographical variation in ethnicity. Forty-six per cent (55% of patients with a confirmed diagnosis) had RA diagnosed at baseline.

### **DAS 28 data**

Nationally, at the point of first specialist assessment, the DAS28 score was calculated for the vast majority of RA patients [2659 (91%)]; when assessed within NHS regions and within Wales, the DAS28 was available for 99% of RA patients in Wales but for only 85% in the South of England. The mean DAS28, the proportion of RA patients with high (>5.1), intermediate (3.2–5.1) and low (<3.2) DAS28 scores and those with missing DAS28 scores at baseline nationally and by NHS region are shown in table 1. The mean baseline DAS28 was 5.0, with little regional variation (4.9

in the Midlands and East of England, 5.1 in the South of England and Wales). Approximately half (45%) of patients had severe disease at presentation; Wales and the Midlands and East of England reported the highest (51%) and lowest (43%) proportion of patients with severe disease activity, respectively.

Table 2 shows these data derived after 3 months of specialist care along with the proportion of RA patients in remission (DAS28 <2.6) and achieving a meaningful reduction in DAS28 [9]. Nationally the proportion of missing data at follow-up increased to 28% (23% in London and the North of England and 39% in Wales). The mean DAS28 for RA patients had decreased to 3.5 for all regions. Twenty-four per cent of RA patients at follow-up were in remission (26% in Wales, 22% in the South of England and Midlands and East of England regions), but 11% still had high disease activity (14% in London, 8% in Wales). Nationally slightly >60% of RA patients with available baseline and follow-up DAS28 scores achieved a meaningful reduction in DAS28 of >1.2; the highest and lowest achievement rates were observed in Wales and the North of England (67%) and the Midlands and East of England (57%), respectively.

### **RAID data**

Table 3 summarizes the national and NHS regional data for RAID scores supplied by all EIA patients at baseline and for those with RA at follow-up. RAID scores indicated generally severe disease activity at the time of diagnosis of an EIA within rheumatology units; the mean score was 5.6 nationally, with a range of 5.5 (South of England) to 5.8 (Wales and the North of England).

RAID data at follow-up were available for 25% of patients with a confirmed RA pattern of disease. The national average RAID score at follow-up was 3.6, with a wider range of scores (mean 3.1 in the North of England to 4.2 in Wales) at follow-up than at baseline. The average reduction in RAID score nationally was 2.4, with the North of England achieving the highest (3.9) and Wales achieving the lowest (1.7) reductions in scores. At 3 months, these mean reductions fall short of the validated minimum clinically important difference for the RAID (defined as a reduction of  $\geq 3$  points or a percentage reduction of 50% from the baseline score) [10].

### **Work data**

Tables 4 and 5 summarize the data received from patients on their ability to work and on whether they recalled being asked about their work. Again, very few patients (748) provided data and there was variation in data across the NHS regions. Twenty-six per cent of the patients 16–65 years of age that returned their patient questionnaires reported that they were not working, but not because of their arthritis, or were undertaking voluntary work. Of the remaining patients of working age who provided data, 7% reported that they were unable to work due to their arthritis, 5% reported that they needed frequent time off work, 16% reported that they occasionally needed time off work, 37% reported that they rarely needed time off work and 42% reported that they had been asked about their work (49% in the South of England and in the Midlands and East of England; 30% in London).

### **PREM data**

Table 6 summarizes the PREM data received nationally and for NHS regions. As for the RAID and work data, only a small number of RA patients (577) completed their questionnaires after 3 months of follow-up; even when these questionnaires were returned, the PREM question was not answered by 17% of patients. Nationally 78% of RA patients providing data agreed with the statement 'Overall in the last 3 months I have had a good experience of care for my arthritis' (87% in London and 76% in the South of England) and <2% disagreed or strongly disagreed. The national and NHS regional findings summarized above disguise considerable variation at the individual trust level.

## **Discussion**

This HQIP-funded audit has provided the first comprehensive national benchmarking of care given to people with newly diagnosed inflammatory arthritis in England and Wales. The population of patients recruited and the number of confirmed diagnoses at first appointment were largely as anticipated, with the majority of patients with a confirmed diagnosis at recruitment having RA.

As reported in the other linked paper [8], data quality was generally good. Data were collected from the vast majority of trusts, but some trusts were unable to recruit the anticipated number of patients. Missing data were a particular problem for patient-derived data and for some of the clinician-derived follow-up data, and this should be borne in mind when interpreting the results.

There were missing data for DAS28 in only 9% of RA patients nationally at baseline, indicating that the vast majority of clinicians are now calculating a DAS28 score for patients seen with RA within the context of the audit. Wales reported DAS28 assessment for virtually all patients, but rates were much lower in the South of England (85%). The variations in DAS28 reporting may reflect variations in practice, but could also be a reflection of data quality, with higher levels of missing data in the South of England. While regular assessment of disease activity, including DAS28, is considered good clinical practice, it only becomes mandatory in the UK when patients need to be assessed for biologic therapy later in the disease course. To be eligible for biologics in the UK, patients are required to have at least two DAS28 scores >5.1, assessed at least 1 month apart, despite the use of at least two conventional DMARDs for at least 6 months. Nationally, and for each region, the highest proportion of RA patients with DAS28 data available had severe or moderate disease activity at presentation (84% nationally).

Patient-derived disease activity measures were available for most EIA patients at baseline. Although the RAID is a validated tool for RA, it assesses domains relevant to all inflammatory arthritis problems and was collected at baseline to ensure that scores were available for all patients that were later established with a diagnosis of RA. As with the clinician-derived assessment (DAS28), the RAID indicated a generally severe level of disease at the point of presentation to secondary care. Ideally, systems need to be implemented to help identify patients with EIA and allow them to be seen within specialist services before their disease has reached severe levels. There was no evidence for significant geographical variation in disease severity at

the first specialist review, but clinicians and patients in Wales reported the highest DAS28 and RAID scores at baseline. The overall range of scores was very wide, however, indicating that, while the majority of patients presented with moderately severe disease, there were patients presenting with very mild but also with very severe disease.

Missing data for the DAS28 score at follow-up hinders interpretation of the results. The available data show that nearly two-thirds of patients achieved a meaningful reduction in their DAS28 score and one-quarter achieved remission after 3 months of specialist care. This suggests that treatments initiated for patients with RA are having an impact in this relatively short time frame of specialist care for most patients. However, these results also show that 11% of patients nationally still have severe disease activity after 3 months of specialist care, highlighting an area for further improvement in the early management of RA in our patient population.

A second RAID score was requested from all RA patients after 3 months of specialist care, but baseline and follow-up data were only available for 509 patients, so again this limits interpretation of the results. Interestingly, although the average DAS28 score was the same across all NHS regions after 3 months of follow-up, there was variation in the average RAID score, from 3.1 to 4.2. In addition, at the population level, greater improvements in DAS28 scores were not mirrored by similar improvements in RAID scores. For example, Wales achieved a meaningful reduction in the DAS28 score in the highest proportion of patients, but also the lowest mean reduction in the RAID score. The RAID score covers more holistic aspects of the impact of disease on an individual, including emotional well-being and coping, than the DAS28, and this may in part explain this discrepancy. Further research into factors influencing response to treatment as recorded by DAS28 and RAID scores could improve our understanding of this particular result.

The lack of a meaningfully clinically important reduction in the RAID score for the majority of patients is disappointing and indicates an area for improvement in managing patient's symptoms and coping strategies in the early stages of their disease. This maps to the failure of the majority of patients to achieve a previously set treatment target [8], and is important. An explanation for this may lie partly in the short follow-up duration of the audit (acknowledging that DMARD therapy often takes >3 months to achieve full effect) and with issues around capacity to provide intensive review and treatment escalation. However, a further consideration is that RA has a serious impact on function and performance that may persist despite apparent control of the inflammatory burden (reflected in good DAS control). This observation highlights the need for rheumatologists to use tools beyond simply the DAS28 or other objective measures of inflammation, such as joint US, when measuring treatment response. Indeed, measures of pain, fatigue and physical function are perhaps the most relevant outcomes for patients, despite being poorly captured in routine care.

The impact of specific treatments (steroids, DMARDs) on DAS28 and RAID scores has not been assessed as part of this audit but is an important area for future research. Whether patient education and support for self-management influences components of the RAID score is also worthy of exploration.

Early arthritis most often presents in people of working age [11]. More than 70% of people recruited to this national audit were <66 years of age. There is overwhelming evidence that established inflammatory arthritis has severe and often permanent effects on work capacity, although there is some evidence that work retention is improving [12]. Health and social care interventions designed to keep people in work are therefore a crucial part of the effective management of inflammatory arthritis. Our data on work-related outcomes are limited because so many participants did not answer the work-related questions. However, the existing data suggest that impact on work capability is small in the very early stages of EIA. This suggests that early disease may be a crucial time for work-related interventions, before work instability translates into long-term work incapacity. The relationship between changing work status, demographic factors and clinical parameters is of interest and worthy of future research.

As emphasized by Dame Professor Carol Black, interventions around work will not happen unless questions about work are part of the clinical consultation [13]. Previous data suggest that providers of rheumatology services believe that those questions are asked [13], but evidence from the National Rheumatoid Arthritis Society [14] suggests that the majority of patients do not recall being asked about work. Data from this national audit echo the findings from the National Rheumatoid Arthritis Society, with only 42% of patients returning the work-related questionnaire recalling being asked about work. Patient recall may be contributing to these statistics, but these data suggest an aspect of care that can readily be improved and may act as a spur for including work issues in the clinical consultation. In support of this important component of patient care, the British Society for Rheumatology is working with Cardiff University to implement a regional training programme across the UK to encourage clinicians to discuss work issues during consultations.

In the absence of a validated composite score for the PREM, responses to the statement 'Overall in the past 3 months I have had a good experience of care for my arthritis' have been reported. The low proportion of RA patients completing their PREM questionnaires after 3 months of follow-up again limits our ability to draw any substantial conclusions from the data supplied. The low data return rate is disappointing, as the PREM is an important source of information on how trusts are meeting the needs of their patients. The low rate of data supply may relate to complexities linked with data collection processes. In order to protect patient confidentiality and encourage honest feedback, completed paper questionnaires had to be returned to individuals not directly involved in the patient's clinical care and then uploaded to the database. These confidential processes may have impaired data capture.

Nearly one-fifth of RA patients failed to supply a response to the question analysed for this report when returning the PREM questionnaire, and the reasons for this are unclear. The PREM questionnaire was originally developed and tested for use after 12 months of specialist care and was modified for use at 3 months for this audit. It is possible that patients did not feel able to provide reasonably detailed feedback on their experiences after just 3 months of care. At the time of finalising the audit questionnaires, there were no alternative validated PREMs.

The PREM data that are available are broadly reassuring; however, trusts are encouraged not to be complacent in interpreting these results. Of some reassurance is the fact that only a small proportion of RA patients (1% nationally) reported that they disagreed or strongly disagreed with

the PREM question on overall quality of care. Trusts receiving such feedback are encouraged to examine the full detail of the PREM data to explore mechanisms for gaining further feedback from patients and to review aspects of service provision that may impact on the patient experience.

Overall, this national audit has provided clinicians with feedback on clinician- and patient-reported outcomes, including information on ability to work, for their patients with RA, and this is the first time such data has been available with national and regional benchmarking. In addition, some limited feedback on patient experiences with rheumatology specialist services has been obtained. This audit has highlighted the difficulties in obtaining data within busy clinic settings and, in particular, highlights the difficulties in obtaining important patient-derived information in such settings.

This audit has revealed a clear need for the NHS to develop better systems for capturing, coding and integrating information from outpatient clinics, including measures of patient experience and outcome and measures of ability to work. This audit is ongoing and further research using the data collected should help improve our understanding of the factors that influence outcome for patients with an EIA and RA.

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Table 1. RA patients with mild, moderate and severe disease activity (DAS28) at the first appointment.

Region	DAS <3.2 at presentation [n (%)]	DAS 3.2 – 5.1 at presentation [n (%)]	DAS >5.1 at presentation [n (%)]	Missing [n (%)]	Mean DAS
National	271 (9.2)	1073 (36.6)	1315 (44.8)	277 (9.4)	5.0 (1.4)
London	24 (8.5)	110 (39.0)	124 (44.0)	24 (8.5)	5.0 (1.4)
Midland & East of England	81 (11.0)	295 (40.1)	316 (42.9)	44 (6.0)	4.9 (1.5)
North of England	90 (9.7)	324 (35.0)	418 (45.1)	94 (10.2)	5.0 (1.5)
South of England	60 (7.6)	261 (33.1)	353 (44.8)	114 (14.5)	5.1 (1.4)
Wales	16 (7.8)	83 (40.7)	104 (51)	1 (0.5)	5.1 (1.3)

Table 2. RA patients with mild, moderate and severe disease activity (DAS28) at follow up.

Region	RA patients recruited at follow up, n	DAS 28 score at FU [mean (SD)]	Remission n (%)	Low disease activity n (%)	Intermediate disease activity n (%)	High disease activity n (%)	Missing data n(%)	Reduction in DAS score by at least 1.2 n (%*)
National level	2026	3.5(1)	480(24%)	196(10%)	571(28%)	217(11%)	562(28%)	780(62%)
London	163	3.5(1)	39(24%)	20(12%)	45(28%)	22(14%)	37(23%)	70(63%)
Midlands and East of England	568	3.5(2)	127(22%)	51(9%)	153(27%)	55(10%)	182(32%)	195(57%)
North Of England	636	3.5(1)	161(25%)	62(10%)	195(31%)	69(11%)	149(23%)	272(67%)
South of England	481	3.5(2)	107(22%)	52(11%)	140(29%)	57(12%)	125(26%)	171(60%)
Wales	178	3.3(1)	46(26%)	11(6%)	38(21%)	14(8%)	69(39%)	72(67%)

Table 3. Mean RA impact of disease scores at baseline and follow up.

Region	All EIA patients with RAID at baseline, n	RAID score at baseline for all EIA patients, mean (SD)	RA patients with RAID score at follow up, n	RAID score at follow up for RA patients, mean (SD)	RA patients with RAID score at baseline and follow up, n	RAID reduction for RA patients, mean (SD)
National	5975	5.6 (2)	552	3.6 (3)	509	2.4 (3)
London	722	5.6 (2)	36	3.3 (3)	32	2.6 (3)
Midlands and East of England	1472	5.6(2)	166	3.9(3)	157	1.9 (3)

North of England	1927	5.8(2)	161	3.1(3)	146	3.9(3)
South of England	1497	5.5(2)	122	3.4(3)	109	2.7(3)
Wales	357	5.8(2)	67	4.2(2)	65	1.7(2)

Table 4. Working age patients not working or needing time off work because of their arthritis.

Region	Not working because of arthritis [n (%)]	Frequent time off [n (%)]	Occasional time off [n (%)]	Rarely needing time off [n (%)]	Not answered [n (%)]
National	54 (7.2)	37 (5.0)	116 (15.5)	273 (36.5)	70 (9.4)
London	5 (8.2)	5 (8.2)	9 (14.8)	18 (29.5)	13 (21.3)
Midland & East of England	19 (9.3)	8 (3.9)	30 (14.7)	89 (43.6)	14 (6.9)
North of England	17 (6.2)	14 (5.1)	45 (16.4)	97 (35.3)	27 (9.8)
South of England	7 (4.4)	8 (5)	26 (16.3)	55 (34.4)	14 (8.8)
Wales	6 (12.5)	2 (4.2)	6 (12.5)	14 (29.2)	2 (4.2)

(N=748 audit participants under the age of 66 who returned a patient follow up form; 198 patients were not working but this was not because of arthritis, or were working in a voluntary capacity only)

Table 5. Working age patients reporting that they recalled being asked about their work by healthcare professionals.

Region	Yes [n (%)]	No [n (%)]	Not answered [n (%)]
National	317 (42.4)	141 (18.9)	290 (38.8)
London	18 (29.5)	11 (18)	32 (52.5)
Midland & East of England	99 (48.5)	39 (19.1)	66 (32.4)
North of England	105 (38.2)	54 (19.6)	116 (42.2)
South of England	78 (48.8)	22 (13.8)	60 (37.5)
Wales	17 (35.4)	15 (31.3)	16 (33.3)

Table 6. RA patients providing responses to the statement 'overall in the past 3 months I have had a good experience of care for my arthritis'.

Region	Agreed [n (%)]	Neither agree nor disagree [n (%)]	Disagree [n (%)]	Not answered [n (%)]
National	391 (78.2)	17 (3.4)	7 (1.4)	85 (17.0)
London	27 (87.1)	0(0)	1 (3.2)	3 (9.7)

Midland & East of England	125 (79.1)	5 (3.2)	3 (1.9)	25 (15.8)
North of England	105 (79.6)	5 (3.8)	0 (0)	22 (16.7)
South of England	86 (75.4)	6 (5.3)	2 (1.8)	20 (17.5)
Wales	48 (73.9)	1 (1.5)	1 (1.5)	15 (23.1)