British Society for Rheumatology

HQIP
Healthcare Quality Improvement Partnership

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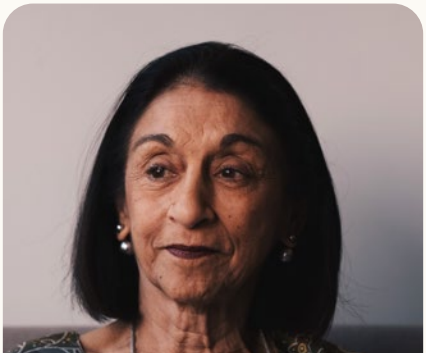
The National Early Inflammatory Arthritis Audit (NEIAA)

Short report on ethnicity
Key findings and recommendations



Based on data collected between May 2018 and March 2020 from specialist rheumatology services in England and Wales

British Society for Rheumatology (BSR) is the UK's leading specialist medical society for rheumatology and musculoskeletal professionals. We support our members to help deliver the best care for their patients, in order to improve the lives of children, young people and adults with rheumatic and musculoskeletal disease. Our members represent the entire profession – from those at the beginning of their career to the most senior consultants, researchers, academics and health professionals in the multi-disciplinary team. Together, they form a powerful voice for paediatric, adolescent and adult rheumatology in the UK.

Healthcare Quality Improvement Partnership (HQIP) commissions The National Early Inflammatory Arthritis Audit (NEIAA) 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 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 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.

The National Early Inflammatory Arthritis Audit (NEIAA) is a programme of work that aims to improve the quality of care for people living with inflammatory arthritis, collecting information on all new patients over the age of 16 referred into specialist rheumatology departments in England and Wales. Spanning the entire patient care pathway, NEIAA includes strong collaboration with patients, as well as healthcare professionals, and aspires to set out a vision for a service that puts patient needs first. To find out more about the NEIAA visit: rheumatology.org.uk/neiaa

This NEIAA short report on ethnicity was prepared by the following people, on behalf of the NEIAA project working group, senior governance group and patient panel (the full list of members are included in the online appendices here: https://arthritisaudit.org.uk/filesuploaded/neiaa%20gov%20membership.pdf).

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Foreword

Dr Sanjeev Patel
BSR President

On behalf of the British Society for Rheumatology, I am delighted to share this report on the link between ethnicity and health outcomes in people with early inflammatory arthritis in England and Wales. Audit data collected before the COVID-19 pandemic (May 2018 to March 2020) are used which makes this the largest dataset to date focusing on this issue. This report takes the place of the annual report, which has been deferred due to the impact of COVID-19 on recruitment to the audit.

These data shed light on the magnitude of the difference in outcomes for people from ethnic minority groups presenting with inflammatory arthritis. Even though people from Black, Asian and ethnic minority groups were younger and less likely to smoke, they still showed less improvement in disease activity scores compared to their white counterparts and had worse mental health outcomes. The reasons for these differences are complex but identifying the needs of ethnic minority groups when planning and providing care is vital. With this important issue moving up the NHS agenda, rheumatology service providers, commissioners, primary care, and importantly patients will all need to work together to address these challenges and improve patient outcomes. The recommendations set out in the report identify the area of focus for each stakeholder and will help us progress in the right direction.

With COVID-19 recovery plans well underway, I would like to encourage you to continue engaging with the audit and uploading data, where possible. These data are invaluable and will help to identify variation in care and opportunities for improvement.

Finally, I would like to thank you all for your continued support of the audit. Please continue to share your achievements as a result of the audit with us.

Patient Story

— Tom's Story

I was being treated by my GP for plantar fasciitis as I had pain in my heel, but one day as I took my short walk to work, I felt a sharp pain in my foot and buckled over. The second time it happened, I collapsed. I decided to go back to my GP who sent me for a blood test. I was then referred to King's College Hospital.

I didn't have to wait long for my first appointment at the early inflammatory arthritis clinic, but when I got my diagnosis of RA, my world crumbled. A few months before this, the community project I'd been working on for over two decades was closed due to funding. It's hard to say whether this had an impact on my physical health, but it certainly had a negative impact on me emotionally.

Further tests and treatment happened very quickly. Waiting for the treatment to start working were the longest weeks of my life, but slowly the pain began to subside.

I've taken many medications over the years to manage my RA and treatment has come on in leaps and bounds since my diagnosis. I'm now on biologics (biologics are newer treatments used to manage disease that is resistant to first line disease modifying medication) and I have good days and bad days. I'm very grateful for my prompt diagnosis and treatment, but I know from my work with other patients that not everyone is so lucky.

I've also had access to fantastic nurses, physios, ophthalmologists and orthopaedics. The nurse helpline at King's has been a particular lifeline for me. It does take a whole team of people to keep me well.

Living with a lifelong condition like RA has taken its toll on my mental health. I was a very active guy and for the first few years I didn't accept my condition and found things very challenging. It makes you re-evaluate your whole life and even the strongest person would find a diagnosis like this tough.

When I was diagnosed 10 years ago, mental health wasn't really something that was talked about. I'm hopeful this has changed, and every patient will get the support they need for both their mental wellbeing and physical health.

This report is incredibly important to highlight the issues that people of colour face. As someone who is mixed race, I'm concerned about the findings and wonder why there are these disparities. My experience mirrors the findings in this report, for example I have noticed less male representation from the Black, Asian and ethnic minority community in services. Whether this is to do with gender, background, culture, embarrassment or education, I'm not sure. But all these issues around inconsistent care, varied outcomes and lack of participation need addressing.

As we look to the future, it's crucial that we strive for equal care for everyone.

Tom Esterine, 60, is a musician from Brixton, South London. He's the former director of the Angell Town community project, an award-winning regeneration scheme. Tom was diagnosed with rheumatoid arthritis (RA) in 2011 and now supports King's College London as an expert patient. Tom is a member of the NEIAA Patient Panel.

Please note: This quote illustrates someone's personal experience and it is not necessarily representative.

Context

Wider NHS context

The association between ethnicity, socioeconomic position and healthcare outcomes has been well established.

A study published in 2020 showed that patients of ethnic minority backgrounds are more likely to report poorer health and have a lower disability-free life expectancy. Ethnic inequalities in Health-Related Quality of Life (HRQoL) were shown to be accompanied by increased prevalence of long-term conditions or multimorbidity, poor experiences of primary care, insufficient support from local services, low patient self-confidence in managing their own health, and high area-level social deprivation [1].

Clinical context

Rheumatoid arthritis (RA) is a chronic autoimmune disease affecting 0.5-1% of the worldwide population [2]. There are very effective treatment options available to suppress the disease process; however, to be effective, therapies need to be introduced early, and escalated using a treat to target approach, as outlined in the **quality standard for rheumatoid arthritis**. Uncontrolled RA can have a significant impact on quality of life and employment and increase societal burden.

Several studies have reported that socioeconomic factors can affect different aspects of RA care, including disease activity scores, patient-reported outcomes (PROMs), access to care, treatment preference and trust in the providers [3-9].

Report aims and scope

To report the relationship between ethnicity and processes of care, and outcomes, in a cohort of patients recruited to the National Early Inflammatory Arthritis Audit (NEIAA). This report presents data describing the association between ethnicity, experience of care as described by the **quality standard for rheumatoid arthritis** and clinician and patient-reported outcomes.

This report serves to empower stakeholders to use audit data to facilitate improvements in quality of care for Black, Asian and ethnic minority patients. The report provides recommendations and encourages providers and commissioners to consider how these can be delivered locally for the benefit of patients and the healthcare system.

Interpreting data

The data for this report were collected from 35,807 patients seen for the first time within specialist rheumatology services between May 2018 and March 2020. NEIAA data collection became non-mandatory from 27 March 2020 due to the COVID-19 pandemic and therefore data submitted after this date were not included in the analysis.

Where denominators for specific indicators vary from the complete relevant cohort, denominators have been provided for context.

Where it was felt that clinical commentary would aid understanding, this has been provided below the key findings of a particular section.

Patient ethnicity was coded according to the standard NHS dictionary as White, Black British/African/Caribbean, Asian/Asian British, mixed and other ethnic groups. For our analyses, ethnicity was also grouped into binary categories of Black, Asian and ethnic minority group including (Black British/African/Caribbean, Asian/Asian British, mixed and other) and White, to draw comparisons between groups. Ethnic subgroup analyses were also conducted to identify the presence of any variation within the Black, Asian and ethnic minority group population that may influence the results of the entire Black, Asian and ethnic minority group cohort. Subgroup analyses, data tables and analysis methodology can be found in a supplementary report **here**.

Intended audience

This report is intended to be read by patients, healthcare professionals, NHS managers, chief executives and board members, and service commissioners, as well as voluntary organisations. BSR strongly advise that rheumatology teams, trusts and health boards discuss these findings with commissioners as a basis for informing future integrated care partnership service development.

Key findings at a glance

Demographics

14%

of patients recruited into the audit were from Black, Asian and ethnic minority populations

(representative of the UK population)

Black, Asian and ethnic minority patients were younger than White patients (median age)

48 yrs

56 yrs

A higher proportion of Black, Asian and ethnic minority patients were female

73%

64%

Clinician-reported outcomes

A lower proportion of Black, Asian and ethnic minority patients were reporting disease remission by three-month follow-up compared to White patients

30%

37%

Patient-reported outcomes

Black, Asian and ethnic minority patients were more likely to report symptoms of anxiety or depression compared to White patients

33%

30%

Key findings at a glance

Quality standards

A higher proportion of Black, Asian and ethnic minority patients were referred to rheumatology services within three working days of presenting compared to White patients **QS33, quality statement 1**


47%

43%

A similar proportion of Black, Asian and ethnic minority patients and White patients were assessed within three weeks of referral **2013 version of QS33, quality statement 2**


43%

42%

A higher proportion of Black, Asian and ethnic minority patients received timely treatment[1] compared to White patients **QS33, quality statement 2**


60%

57%

A high proportion of both groups of patients were provided with disease-related education **QS33, quality statement 3**


93%

94%

A high proportion of both groups of patients were able to access care in case of emergencies **QS33, quality statement 4**


91%

93%

A lower proportion of Black, Asian and ethnic minority patients received a formal annual review compared to White patients **QS33, quality statement 5**


34%

46%

[1] Starting conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within six weeks of referral

Recommendations

Rheumatology service providers

1. Services should explore local data and work with Black, Asian and ethnic minority patients and their families, and referrers to better understand and overcome barriers to them receiving optimal care and improved care outcomes as set out by the quality standard for rheumatoid arthritis **(QS33)**.
2. Services should ensure that Black, Asian and ethnic minority patients are supported to achieve disease remission within three months by
    a. increasing the % of Black, Asian and ethnic minority patients receiving treatment in a timely manner **(QS33: quality statement 2).**
    b. providing monthly reviews until treatment targets are met **(QS33: quality statement 3).**
    c. providing culturally appropriate disease-related education and support **(QS33: quality statement 4).**
    d. providing information and referral to local services to support self-management, including mental health **(QS33: quality statement 4)**.
3. Services should ensure patients are offered and encouraged to attend a formal 12-month review **(QS33: quality statement 5).**

Commissioners, health boards, policy makers

4. Work with services to ensure they are aware of and understand the cultural needs of their patients to ensure the best possible health outcomes for Black, Asian and ethnic minority patients.
5. Ensure that services are resourced appropriately to facilitate the provision of person-centred equitable care.

Primary care

6. Discuss disease implications with Black, Asian and ethnic minority patients in a culturally appropriate manner to improve engagement with rheumatology services post referral.

Patients/carers

7. If you suspect you have inflammatory arthritis, ask your GP for a referral to a specialist rheumatology service within three working days **(QS33: quality statement 1).**
8. If you are given a diagnosis of rheumatoid arthritis, work with your rheumatology team to begin treatment within six weeks and attend monthly monitoring appointments until your treatment target is met **(QS33: quality statement 2).**
9. Ask your rheumatology service for a formal 12-month review **(QS33: quality statement 5).**
10. Ask for information and referral to local services, if appropriate, to support you to manage your condition, including your mental health **(QS33: quality statement 4).**

Section 01

Demographics and baseline clinical data

Key findings

14%

(5164) of patients recruited into the audit were from Black, Asian and ethnic minority populations (this is representative of the UK population according to the latest ONS report [10]).

- Black, Asian and ethnic minority patients were younger than White patients (median age 48 compared to 56 years).
- A higher proportion of Black, Asian and ethnic minority patients were female (73% [3783] compared to 64% [19,717]).
- White patients were more likely to be current or ex-smokers (18% [5502] and 27% [8376]) compared to Black, Asian and ethnic minority patients (11% [551] and 11% [544]).
- A higher proportion of Black, Asian and ethnic minority patients were in paid work >20h/ week (50% [2475/4908]) compared to White patients (49% [14,466/29,369]) but overall work impairment seemed to be similar in both groups[2].
- 73% (21,486/29,646) of White and 69% (3438/4970) of Black, Asian and ethnic minority patients had symptoms for up to 12 months prior to referral.
- 65% (19,818/29,846) of White and 70% (3613/5067) of Black, Asian and ethnic minority patients were referred via an early arthritis pathway.

The conversion rate for patients enrolled in NEIAA (i.e. the number of patients referred with suspected EIA compared to the number of patients confirmed to have EIA) was 31% for Black, Asian and ethnic minority patients (1640/5164) and 37% for White patients (11,315/30,643)[3].

Of patients eligible for follow up:

- Working diagnosis for both groups was primarily RA – see table 1
- 63% (927/1474) of Black, Asian and ethnic minority and 56% (5744/10,224) of White patients had a positive cyclic citrullinated peptide (CCP) or Rheumatoid factor result (RhF) test
- No comorbidities were reported for 67% (1074/1605) of Black, Asian and ethnic minority patients compared to 57% (6376/11,187) of White patients. 16% (258/1605) of Black, Asian and ethnic minority patients and 21% (2327/11,187) of White patients reported two or more comorbidities.
- The median baseline DAS28[4] scores were very similar between groups indicating moderate disease activity (4.8 in Black, Asian and ethnic minority patients and 4.7 in White patients)

[2] Measured using the Work Productivity and Activity Index (WPAI) overall impairment score, which incorporates absenteeism (percentage of work hours missed in relation to total hours worked) and presenteeism (extent by which patient' work productivity was affected by their health).

[3] Conversion rates are presented for those patients that had eligibility data present.

[4] Disease Activity Score-28 (DAS28) is calculated using several markers of disease activity, including tender joint count, swollen joint count, patient-reported global assessment score, CRP (C-reactive protein) and/or ESR (erythrocyte sedimentation rate). The DAS28 is used to categorise disease activity as remission (0 - <2.6), low disease activity (2.6 - ≤3.2, moderate disease activity (>3.2 - ≤ 5.1) and high disease activity (>5.1).

Section 01

Demographics and baseline clinical data

Table 1 on working diagnosis for EIA patients

What is your working diagnosis	Total: n (%)	White patients	Black, Asian and ethnic minority patients
Axial Spondyloarthritis	826 (2%)	716 (2%)	110 (2%)
Connective Tissue Disease	479 (1%)	353 (1%)	126 (3%)
Crystal Arthritis	1218 (4%)	1105 (4%)	113 (2%)
Fibromyalgia	1322 (4%)	1112 (4%)	210 (4%)
Mechanical Back Pain	391 (1%)	319 (1%)	72 (1%)
Osteoarthritis	6346 (19%)	5558 (19%)	788 (16%)
Psoriatic Arthritis	2747 (8%)	2469 (8%)	278 (6%)
Reactive Arthritis	890 (3%)	777 (3%)	113 (2%)
Rheumatoid Arthritis	9570 (28%)	8293 (28%)	1277 (26%)
Undifferentiated Arthritis	3443 (10%)	2995 (10%)	448 (9%)
Other	6846 (20%)	5517 (19%)	1329 (27%)

Section 02

Key findings

- 47% (2333/4964) of Black, Asian and ethnic minority patients and 43% (12,561/29,417) of White patients were referred to rheumatology services within three working days of presenting **QS33, quality statement 1.**
- 43% (2184/5067) of Black, Asian and ethnic minority patients and 42% (12,619/30,117) of White patients were assessed within three weeks of referral **2013 version of QS33, quality statement 2.**

Of patients eligible for follow up (1640 Black, Asian and ethnic minority patients/11,315 White patients):

- A higher proportion of Black, Asian and ethnic minority patients (60% [723/1204]) received timely treatment[5] compared to White patients (57% [4919/8695]) **QS33, quality statement 2**.
- A high proportion of both groups of patients were provided with disease-related education (93%, [1465/1575] of Black, Asian and ethnic minority patients and 94% [10,447/11,061] of White patients) **QS33, quality statement 3**.
- 34% (179/520) of Black, Asian and ethnic minority patients and 46% (1914/4175) of White patients received a formal annual review **QS33, quality statement 5**.

Clinician reported outcomes:

- The median three-month follow-up DAS28[6] scores were 3.4 in Black, Asian and ethnic minority patients, indicating moderate disease activity and 3.1 in White patients, indicating low disease activity.
- A lower proportion of Black, Asian and ethnic minority patients reported disease remission by 3-month follow-up compared to White patients (30% [280/921] compared to 37% [2650/7125]).
- A lower proportion of Black, Asian and ethnic minority patients were reporting a good or moderate EULAR[7] response compared to White patients (63% [561/892] compared to 67% [4631/6900]).

Patient reported outcomes:

- Black, Asian and ethnic minority patients were more likely to report symptoms of anxiety or depression compared to White patients (33% [66/198] compared to 30% [772/2608]).
- The proportion of Black, Asian and ethnic minority patients missing >1 workday in one month was lower when compared to White patients (14% [15/110] compared to 18% [214/1176]).
- Black, Asian and ethnic minority patients reported poorer musculoskeletal health compared to White patients (median score on MSKHQ[8] questionnaire was 34.5 for Black, Asian and ethnic minority patients compared to 36 for White patients).

[5] Starting conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within 6 weeks of referral

[6] Disease Activity Score-28 (DAS28) is calculated using several markers of disease activity, including tender joint count, swollen joint count, patient-reported global assessment score, CRP (C-reactive protein) and/or ESR (erythrocyte sedimentation rate). The DAS28 is used to categorise disease activity as remission (0 - <2.6), low disease activity (2.6 - ≤3.2, moderate disease activity (>3.2 - ≤ 5.1) and high disease activity (>5.1).

[7] European League Against Rheumatism (EULAR) disease response data were reported using the change in DAS28 categories of no response (≤0.6), moderate response (>0.6 to ≤ 1.2), and good response (> 1.2).

[8] Musculoskeletal Health Questionnaire (MSK-HQ). MSK-HQ is a 15-item questionnaire that evaluates how musculoskeletal symptoms affect day to day life. Scores range from 0-56, higher scores indicating better MSK health. No MCID is defined for this tool.

These are real world data describing for the first time the magnitude of differences in outcome for Black, Asian and ethnic minority patients with new presentations of inflammatory arthritis in England and Wales. Efforts have been underway for the last decade to try and close the gap in outcomes for Black, Asian and ethnic minority patients [11, 12]. However, this NEIAA report shows that differences in clinical outcomes still exist.

The care experienced by Black, Asian and ethnic minority patients only aligns well to two statements of the quality standard; provision of education and access to care in emergencies **(QS33, statement 3 and 4)**. It is worth noting, though, that these are clinician-reported data. Referral **(statement 1)**, assessment **(statement in 2013 version of standard)**, access to timely treatment **(statement 2)** and 12-month follow-up **(statement 5)**, although not too dissimilar between the different groups of patients in our report and sometimes better for the Black, Asian and ethnic minority group, are still below best practice standards. Moreover, several clinical outcomes are worse for Black, Asian and ethnic minority patients.

Our current knowledge suggests that attainment of these quality standard metrics corresponds to a higher chance of clinical remission by three months (both based upon previous clinical trial data as well as our own NEIAA analyses) [13, 14]. However, Black, Asian and ethnic minority patients included in this NEIAA report were less likely than White patients to achieve remission by three months despite the quality standard performance appearing similar, if not better, in some cases. This is consistent with findings from US observational studies where ethnic minorities were less likely to achieve remission than white patients [7]. This could be due to several reasons that have not been explored in this report such as social deprivation, education, health-seeking behaviour, treatment tolerance and adherence or genetic factors.

Conclusion

Process measure performance suggests that there is equality in provision of care at the start of the patient journey, but the outcomes highlight the imbalance in equity. Disease remission after three months was different between groups in our report, as was the likelihood of reporting symptoms of anxiety and depression. Differences in use and uptake of care may explain our findings, or this could be the result of genetics and/or cultural factors. The difference between equality and equity within this report is an important finding that must be highlighted. Although equality and equity both promote fairness, equality achieves this through treating everyone the same regardless of need, while equity achieves this through treating people differently according to need. Understanding this difference may be the key to delivering the best care for all, closing the health gap.

The degree of incomplete data is an important factor to acknowledge, particularly for PROM and work data.

Acknowledgements

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

King's College London
The Centre for Rheumatic Diseases at King's College London has provided methodological and analytical support for NEIAA from its outset.

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Appendix 1

Quality Standards

Rheumatoid arthritis in over 16s: Quality standard [QS33] (2013, updated 2020):
This quality standard covers assessing, diagnosing and managing RA in over 16s. It describes high-quality care in priority areas for improvement.

Quality statement	Description
Statement 1	Adults with suspected persistent synovitis affecting more than 1 joint, or the small joints of the hands and feet, are referred to rheumatology services within three working days of presenting in primary care. [2013, updated 2020]
Statement 2	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. [2013, updated 2020]
Statement 3	Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management. [2013, updated 2020]
Statement 4	Adults with rheumatoid arthritis and disease flares or possible treatment-related side effects receive advice within one working day of contacting rheumatology services. [2013, updated 2020]
Statement 5	Adults with rheumatoid arthritis have a comprehensive annual review that is coordinated by rheumatology services. [2013, updated 2020]
The following statement from the 2013 quality standard for RA in over 16s is still supported by the evidence and may still be useful at a local level. Therefore, we have chosen to report the relevant data to support teams in local quality improvement.	
N/A	People with suspected persistent synovitis are assessed in a rheumatology service within three weeks of referral.

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