

## Debate paper

# Tinkering at the edges or collaborative symbiosis? Ethnicity and rheumatology: a consensual review discussion

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### What is known on this subject

- The UK is recognised as a pluralistic society with a growing black and minority ethnic population.
- A number of rheumatological conditions may display variation between ethnic groups with regard to epidemiology, patterns of ill health and outcomes.
- To date there has been little focus on issues of diversity and ethnicity in publications arising from rheumatological research or clinical conferences.

**What this paper adds**

- A focused survey of the published medical literature and expert opinion on ethnicity and rheumatology suggests a divergence of disease patterns and ill health from traditional westernised models.
- Culturally held perceptions and beliefs, as well as delay in presentation and referral for specialist intervention for rheumatoid arthritis, present barriers to optimising healthcare for South Asians.
- Experiential data from a professional workshop discussion emphasise the need for an urgent, distinct focus on public-consumer engagement, information, education and research with regard to ethnicity and rheumatology.
- Focused professional workshops can provide an opportunity to develop consensus among clinicians and researchers with regard to rarely researched and under-reported topics.

**ABSTRACT**

It is recognised that the epidemiology of disease as well as ill-health manifestations in minority populations may be at variance from orthodox formulations generated through traditional research and as described in the western medical literature. The relevance of this lies in the need to devise strategies for optimising healthcare in minority groups, which, in the UK, is a duty that has been imposed upon providers through the passage of legislation. This paper examines the effect of ethnicity on three common rheumatological conditions, namely rheumatoid arthritis, psoriatic arthropathy and osteoporosis, and concludes that a range of ethnic-specific issues have as yet failed to receive adequate attention in medical research, and, in addition, that

there is a lacuna in comprehensive national strategies aimed at addressing health needs within this particular area. Approaches to remedying this deficiency are suggested based on information obtained through the lens of theme-specific workshops consisting of a mix of experienced healthcare professionals engaged in the care of individuals with rheumatological conditions. Multifaceted strategies need to be deployed to improve healthcare and to further the agenda of minority health issues in rheumatology.

**Keywords:** ethnology, osteoporosis, psoriatic arthritis, rheumatoid arthritis, rheumatology, South Asian

**Introduction**

The UK is recognised as a multiethnic pluralistic society, with approximately 12% of the population in England reporting their ethnic origin as non-white (UK National Statistics, 2007). It is well recognised that a range of factors linked to ethnicity may have an impact on the pattern and outcome of the disease in a number of rheumatological conditions (Kumar and Klocke, 2010). Typical examples include rheumatoid arthritis (Samanta *et al*, 2005) and systemic lupus erythematosus (Samanta *et al*, 1991, 1992). Language, social beliefs and cultural attitudes may further affect disease management, impact and/or outcome in minority groups. Furthermore, research has consistently highlighted inequalities in healthcare (Johnson, 2003), access to care and adequate needs assessment (Gill *et al*, 2002). Addressing the needs of the black and minority ethnic populations afflicted by conditions that require long-term care can be complex, as these communities have a diverse set of social beliefs and values, language and cultural attitudes. Simply ensur-

ing effective and appropriate patient education, health literacy and true self-efficacy in these populations is a major challenge (Adebajo *et al*, 2004). An efficient delivery of healthcare with a focus on quality will require planning by policy makers and providers to eliminate health inequalities.

Although minority ethnic health has been recognised as a challenge for the NHS and publicly articulated as such for the better part of a quarter of a century (Bhopal and Donaldson, 1988), the health agenda for tackling these issues remains shaky. Diseases that fall within a long-term care model are associated with a higher mortality, and although there has been a thrust towards addressing these inequalities in coronary heart disease and diabetes in South Asians (Bhopal *et al*, 2002), the focus on rheumatic conditions has been lamentably limited (Samanta *et al*, 2005). Within the broader canvas of rheumatology, in the view of the authors, the approach to minority ethnic health has encompassed sporadic bursts from committed and interested individuals, rather than reflecting the engagement of healthcare in its comprehensive sense through a coherent and systematic wider

strategy. In view of this, and the duties placed on public sector services to avoid discrimination, as set out, for example, by the Stephen Lawrence Inquiry (Macpherson, 1999), the Race Relations (Amendment) Act 2000 and the Equality Act (2010) and other domestic and European legislation on human rights, it was considered that it might be helpful, as a starting point, to organise a conference on ethnicity and rheumatology in order to engage key workers and pull together the diverse strands in this area. A conference was therefore held in Leicester, and the output from that event forms the basis of this paper, which also provides the first opportunity for these issues to be debated within an academic peer-reviewed journal setting.

## Rheumatoid arthritis in South Asians

### Delay in presentation and referral

Current thinking in rheumatology and national guidelines champion the principle of early diagnosis and treatment of rheumatoid arthritis with specific disease-modifying anti-rheumatic drugs (DMARDs), ideally within 3 months of the onset of symptoms (Nell *et al*, 2004; National Institute for Health and Clinical Excellence, 2009). Yet in the case of South Asian patients, there seems to be a disproportionate delay. A multicentre audit of rheumatoid arthritis in minority ethnic groups was undertaken in four centres with a large minority ethnic population (Sheffield, Romford, Nottingham and Leicester). The results show that a high proportion (62%;  $n = 68$ ) exceed the 3-month time interval for specialist referral, and there was a delay in the initiation of DMARD therapy of more than 3 months, more than 6 months and more than 9 months in 8%, 1%, and 10%, respectively, of South Asian patients (Panchal *et al*, 2012).

A significant delay in the time taken for presentation of South Asian patients with early rheumatoid arthritis to primary care physicians has been reported from Birmingham (Kumar *et al*, 2010). The median time taken for presentation to primary care was 24 weeks after the onset of symptoms for South Asians, compared with 12 weeks for non-South Asian patients (Kumar *et al*, 2010). The time taken for patients to progress through the management pathway at primary care level (i.e. the time from assessment in primary care to referral to secondary care) and at the secondary care level (i.e. the time from referral from primary care to assessment by a rheumatologist) was not significantly different between South Asians and non-South Asians. This was a median period of 2 weeks for both groups at the level of primary care and a

median period of 4 weeks compared with 3 weeks for South Asians and non-South Asians, respectively, at the level of secondary care (Kumar *et al*, 2010). The main factors that influenced South Asian patients' decisions to seek medical advice can broadly be divided into four categories, namely the severity of symptoms and their impact on functional ability, the individual patient's own explanation for their symptoms and recognition of their significance, knowledge of rheumatoid arthritis and the available therapies, and subjective experience of attitudes towards healthcare providers (Sheppard *et al*, 2008).

Causal factors that were likely to lead to a delay in presentation to a healthcare practitioner after the onset of symptoms were identified as mainly patient-centred and linked to cultural attitudes and self-management strategies. Attitudinal factors included beliefs such as the disease being a result of God's will, the negative influence of family and friends, denial due to the possibility of social stigmatisation, and a lack of confidence in the efficacy of medication. Patients of South Asian origin have been shown to have negative beliefs about their medication. A recent survey in Birmingham showed that South Asians had more concerns about DMARDs than white British patients, and believed that medicines in general were more harmful and overused. This could have implications for optimal disease control (Kumar *et al*, 2008, 2011a). Consequently, self-management strategies were often initially deployed instead of seeking medical advice. These strategies included dietary manipulation and the exclusion of certain foods, as well as the use of alternative therapies, particularly Indian homeopathy, prayer, meditation and positive thinking, lifestyle adaptations, and physical therapy (both massage and topical application of heat and cold) (Kett *et al*, 2010).

A number of strategies have been suggested in an attempt to encourage South Asian patients with rheumatoid arthritis to seek early medical advice. These include the development of written and audiovisual patient information in different languages and its dissemination through workshops in the local community as well as other media, such as radio and films. Patient support structures such as user groups and a telephone helpline for minority ethnic people who speak languages other than English (Kumar *et al*, 2009, 2011b) have been suggested by the Birmingham Arthritis Resource Centre (2006) as further strategies.

### Disease perception and information needs

Patient interpretation of disease activity is significantly influenced by ethnic origin, and evolves from appropriate knowledge and education about disease processes (Bruce *et al*, 2007). A cross-sectional study

of 107 South Asian patients with rheumatoid arthritis showed that, compared with age- and gender-matched controls, they experienced more pain and disability than patients of North European origin (Griffiths *et al*, 2000). This finding has been supported by further studies, including that of Ghelani *et al* (2011).

Although there is considerable information available for patients about rheumatological conditions, this may not always be culturally appropriate, and is therefore of limited use or benefit to members of minority groups, as has been demonstrated with regard to material pertaining to osteomalacia (Samanta *et al*, 2009). In order to gain a better understanding of the information needs of South Asians with regard to rheumatoid arthritis, a collaborative investigation was conducted by the University Hospitals of Leicester and the Mary Seacole Research Centre at De Montfort University. Five separate language focus group discussions from South Asian communities were conducted in Gujarati, Punjabi, Urdu, Bangladeshi and Katchi (a dialect of Gujarati spoken in the area adjoining the southern boundary of Pakistan and India). The groups were led by experienced facilitators from South Asian communities who were initially given a half-day training session about rheumatoid arthritis, delivered in simple lay language, and were provided with key trigger questions and prompts to encourage discussion. The discussion was audio recorded and contemporaneous notes were taken. The raw data were transcribed and content analysed by two independent researchers for thematic and sub-thematic derivations.

The following areas were identified where information about rheumatoid arthritis could be made more ethnically specific and culturally competent.

- *Perception of rheumatoid arthritis.* There was a generalised belief that arthritis in its wider sense was causally dependent upon non-medical factors. These included divine intervention, the type of clothes worn and the work that a person might undertake. Food was regarded as a key factor that could influence the outcome of arthritis without the need for medical intervention. 'Good foods' included ginger, garlic, goat's feet and honey. 'Bad foods' included acidic substances (lemon, vinegar, tomato) and left-over food. 'Arthritis' was regarded as a single entity, and there was a lack of awareness even of the difference between rheumatoid arthritis and osteoarthritis. Furthermore, the concept of arthritis was confused with that of osteoporosis.
- *Communication.* Pain in the joints was often described in terms of 'heat' and 'body warmth.' There was a feeling that linguistic barriers would be an

impediment to obtaining sound professional advice, as translation either by a family member or through the attendant healthcare professional was perceived as being unsatisfactory.

- *Support.* There was little awareness of information about rheumatoid arthritis, or knowledge of how to access such information. Illustrated or audio-visual information was regarded as being superior to written material. There was no awareness of any support groups.
- *Alternative therapy.* There was a general lack of confidence in the efficacy of medication. Alternative (non-allopathic or non-prescribed drug) therapies were the preferred option. These therapies included herbal and natural remedies, imported herbal medication and Ayurvedic treatment. There was an appetite for exploring the availability of Ayurvedic treatment locally within the UK, as well as in India.
- *Social impact.* Chronic disease, and arthritis in particular, was regarded as socially stigmatising. There was a clear message that this could have an adverse effect on familial relationships, particularly for young women. Emphasis was placed on the negative impact on marriage prospects, as well as how this might adversely affect a daughter-in-law who has 'come into the family.' Lack of mobility, along with the need for regular long-term medication and hospital attendance, was seen as a mark of social inferiority. There was also some suggestion that joint problems might affect the performance of religious rituals such as actions associated with prayer.

## Disease treatment

In a UK-based retrospective study of ethnic differences in response to DMARDs among patients with inflammatory arthritis, people of South Asian ethnicity stopped therapy sooner than Northern Europeans (Helliwell and Ibrahim, 2003). Possible explanations included problems with effective communication, and cultural differences in expectations and response to illness (Odotola and Ward, 2005).

Although much of the available patient-oriented information on rheumatoid arthritis in the UK is of a high standard, it would nonetheless appear that it lacks a range of culturally specific components that would help to dispel myths about rheumatoid arthritis and facilitate a culturally competent information base. This is an issue that needs to be carefully considered and addressed.

## Psoriatic arthropathy

Psoriatic arthropathy was first recognised as a distinct clinical entity by the American College of Rheumatology in 1964 (O'Neill and Silman, 1994). There is a plethora of data on the incidence and prevalence of this disease, yet only a few studies have described the ethnic influences. The overall prevalence is in the range 20–420 per 100 000 members of the population in Europe and the USA, and the incidence is in the range 3–23.1% of the population (Almanos *et al*, 2008). Data from Asia show a prevalence of 10–100 per 100 000 in China and 0.1–1 per 100 000 in Japan (Tam *et al*, 2009). However, in the Indian population of Singapore, psoriatic arthropathy is more common than in the Chinese population (Tam *et al*, 2009). An earlier study by Thumboo *et al* (1997) acknowledged Indian ethnicity as a risk factor for arthritis in Singapore (OR, 2.39; 95% CI, 1.02–5.60).

The gender distribution of psoriatic arthropathy is equal in western populations, but the condition is said to be more common among women in Eastern populations. Further significant clinical differences in ethnic groups include the fact that arthritis mutilans is rarely reported in Asian studies, but lumbar spondylitis is significantly more common in Indian populations than in Chinese populations in Singapore (Thumboo *et al*, 1997). Eye involvement is very rare among Asians, although nail lesions are more common and an increased prevalence of subclinical atherosclerosis has been reported in Asian patients with psoriatic arthropathy (Tam *et al*, 2009).

A cross-sectional observational study to determine whether psoriatic arthropathy in South Asians (Gujarati Indians) differs from that in the white population recruited 60 patients in each group, and a range of demographic and clinical data were collected. There was no significant difference between the two groups in mean age, gender or Psoriasis Area and Severity Index score. South Asian patients had significantly higher tender and swollen joint counts, plasma viscosity and pain scores. They also scored higher on the Health Assessment Questionnaire and on physician global assessment of disease activity. The use of DMARDs was similar in the two groups, with methotrexate and sulphasalazine being most commonly used (Malipeddi and Hassan, 2011).

This report is one of the first studies to examine clinical differences between South Asians and the white population in the UK with regard to psoriatic arthropathy. The results suggest that there may be subtle but significant differences in the South Asian group which may need further consideration in terms of disease management and patient support.

## Osteoporosis

An observational cross-sectional study of Gujarati people in Leicester, where they form the largest minority ethnic group, showed that bone mineral density (BMD) is lower than in the local white population (Hamson *et al*, 2003). BMD was significantly lower among the Gujarati women both in the spine and at the hip, compared with that in their white counterparts. For Gujarati men, there was a trend towards a lower BMD at the hip than in the spine. Cigarette smoking and alcohol consumption were both higher among the white participants, and exposure to sunlight (more than 4 hours per day) was significantly higher in white participants compared with South Asians. However, there were no significant differences in the mean level of serum calcium or alkaline phosphatase between South Asian and white participants, although a significantly higher proportion of both men and women in the South Asian group had a vitamin D level that was not measurable (i.e. it was below the lower limit of the laboratory range of normal). Vitamin D levels have a positive influence on bone mineral density in a small population of Pakistani women aged 18–36 years living in the Greater Manchester area (Roy *et al*, 2007).

There is worldwide variation in hip fractures, with the highest reported prevalence occurring in North America and Europe (Dhanwal *et al*, 2010). The prevalence in North America has been reported to be as high as 15% in the indigenous population, but only 2.4% in the Hispanic population (Dhanwal *et al*, 2010). The incidence of osteoporotic fractures in black Africans appears to be low (Adebajo *et al*, 1991). In Europe, the highest prevalence of hip fractures has been recorded in Sweden (Dhanwal *et al*, 2010). Fractures are more common in white women than in men (Melton *et al*, 1992, 1998; surprisingly, we were unable to locate any more recent references on this issue). The principal studies on osteoporosis and bone mineral density relate to the white population, and there are few comparable data for minority ethnic groups. This shortage could provide fertile ground for future inquiry, and may have implications for access to resources, including diagnosis and treatment. In a recent case series study that examined the various experiences of South Asian women with osteoporosis, no first-generation South Asians reported using the National Osteoporosis Society (NOS) support services. First-generation South Asians did not contact the NOS services because they anticipated that they would not be able to speak or read the materials in their own language (McKenna and Ludwig, 2008).

## Future trajectories

A major part of the conference at which these findings were presented was devoted to three workshops, which allowed delegates to share their experiences and express their opinions. The themes of the workshops were 'Patient and Public Involvement', 'Education', and 'Research in Respect of Rheumatology and Minority Ethnic Populations.' The participants were divided into groups of approximately eight mixed professionals, and each group rotated through each of the workshops for a specified period of time (30 minutes). The workshops were led by experienced facilitators, who used neutral cues and prompts to stimulate discussion. Contemporaneous notes were made about the discussion in each of the workshops. These were fed back to the participants at a post-workshop plenary session. Further discussion points were noted, and data relevant to each of the workshops were collated and analysed in order to develop key messages as described below. It is believed that these messages reflect an enriched variegation of experience and opinion from a number of skilled practitioners across a broad section that transects the spectrum of healthcare.

The *patient and public involvement* discussions proposed the development of patient support groups for members of minority ethnic populations. The model proposed having a 'champion' physician as the lead, and having regular meetings based in the community rather than in secondary or primary care settings. Patient education should focus on ethnic-specific counselling sessions prior to the initiation of DMARD therapy, establishing realistic outcomes at the start of treatment, and the needs of different age groups.

The key messages from the *education* discussions were principally about developing audiovisual, language-specific and culturally competent information about rheumatoid arthritis for patients and the public, and promoting this in the non-healthcare setting through community groups and religious organisations. Education should be a reciprocal process. Patients needed education about the treatment and management of their arthritis that took into account their particular beliefs. Professionals needed to learn about patients' cultural values, sensitivities and beliefs with a view to becoming culturally competent. The value of expert patient groups within an ethnicity framework was emphasised.

The *research* discussions focused on modalities geared towards changing patients' perception of rheumatoid arthritis, developing an understanding of the disease, and an acceptance of and concordance with DMARD therapy. There was a powerful thrust towards offering real-life experiences through an audiovisual

medium. Ideas for research focused on rheumatoid arthritis, connective tissue disease and metabolic bone disease. It was generally thought that funding for rheumatic diseases, and in particular for ethnicity within rheumatic diseases, was woefully inadequate, but that it should be channelled through respected organisations such as Arthritis Research UK, the National Institute for Health Research (NIHR), the British Society of Rheumatology (BSR) and the National Rheumatoid Arthritis Society (NRAS). An entrepreneurial approach to obtaining funding from settled South Asian industrialists initially provoked strong feelings, but on reflection was regarded as a possibility for future exploration.

## Conclusion

All NHS staff have a legal requirement to address ethnic and race-related inequalities in healthcare provision in accordance with the Race Relations (Amendment) Act 2000 and the Equality Act 2010. The evidence base for service provision and the use of healthcare services by minority ethnic groups with regard to rheumatic conditions is currently tenuous. Within Leicester, where 40% of the population is of minority ethnic origin, one national commissioning board is to be established in 2013 with a broad representation consisting primarily of senior doctors. The average age of the minority ethnic population is approximately 8 years younger than that of the national population, and Gujarati is the commonest non-English language. It is recognised that the life expectancy in the Gujarati group locally is approximately 2 years less than the national average, and that those with rheumatoid arthritis are at risk of cardiovascular disease. Yet, disappointingly, there are currently no assurances of any financial commitment within the commissioning budget, even for an area with such a large minority ethnic population. Although national organisations such as the South Asian Health Foundation, as well as specialist societies, are endeavouring to lobby the government to take action, much still remains to be done.

An in-depth review of published evidence relating to ethnic health and disease has identified a number of key issues, which include the need for interpreter and translation services, a focus on ethnically specific diseases and variations, and the cost of treating such conditions in minority ethnic populations (Atkinson *et al*, 2001). Commissioning models would need to take into account the additional costs incurred in meeting such needs. There is currently considerable variation in terms of operational services and the strategic approach taken by budget holders. It is hoped that the new commissioning services might take

cognisance of the implications that ethnic diversity may have for the services that they provide, and factor these into budgetary accountability.

The keys to providing ethnic-specific healthcare are the concepts of *cultural sensitivity* and *cultural competence* (Samanta *et al*, 2009). Cultural sensitivity refers to professional awareness and knowledge of the evidence base for caring for members of a particular community. Cultural competence refers to the application of this knowledge through a process that evaluates, refines and redevelops skills so that healthcare is provided in ways that are both acceptable and meaningful to the recipients.

Concerns about the scientific rigour and meaningfulness of healthcare research in ethnicity have increased in proportion to the volume of such work that is being undertaken (Salway *et al*, 2011). Most studies tend to end with the trite phraseology that 'further work in the area is needed.' Although this conclusion invokes conventional plaudits, nothing will be achieved without a determination to bring about change. Rheumatology needs to be absorbed and contextualised on to the wider canvas of strategic thinking and development by those who are involved in framing policy for minority ethnic health issues. We need to stop tinkering at the edges, and instead to develop a serious collaborative symbiosis to further the agenda of minority health issues in rheumatology.

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#### CONFLICTS OF INTEREST

AS and AM have accepted speaker fees and sponsorship from pharmaceutical companies. IP has accepted speaker fees and sponsorship from pharmaceutical companies, and has been on various advisory boards. AR works as Medical Director in a commissioning primary care trust.

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## Appendix

### Ethnicity in rheumatology

Venue: King Power Stadium Leicester, Filbert Way,  
Leicester LE2 7FL  
Date: 2 December 2011  
Convenor: Dr Ash Samanta, Consultant Rheumatologist,  
University Hospitals of Leicester NHS Trust

### Programme

09.00–09.30 Arrival, registration, coffee

*Chair: Dr A Samanta*

09.30–09.40	Welcome	Dr A Samanta
09.40–09.50	Ethnic diversity in Leicester and possible impact on future commissioning intentions	Prof. A Rashid
09.50–10.00	An audit of rheumatoid arthritis in minority ethnic groups	Dr S Panchal
10.00–10.30	Challenges in the management of rheumatoid arthritis in South Asians	Ms K Kumar
10.30–11.00	Knowledge needs and perception of South Asians regarding rheumatoid arthritis	Dr A Moorthy
11.00–11.30	Psoriatic arthritis in minority ethnic groups	Dr W Hassan
11.30–12.00	Minority ethnic groups and osteoporosis	Dr I Pande
12.00–13.00	Lunch	

*Chair: Prof. K Chakravarty and Prof. M Johnson*

13.00–13.15	Introduction to workshops/discussion groups for rheumatological conditions	
13.15–14.30	Workshop I: Education for minority ethnic patients	Facilitator: Prof. M Johnson
	Workshop II: Patient and public involvement from minority ethnic groups	Facilitator: Dr A Moorthy
	Workshop III: Research in minority ethnic groups	Facilitator: Dr W Hassan

*Chair: Prof. K Chakravarty and Prof. M Johnson*

14.45–15.45	Feedback from workshops/discussion groups	
15.45–16.00	Conclusion and thanks	Dr A Samanta

