

**Title:** To explore the ageing South Asian patients' perceptions of biologics/anti-tumour necrosis factor (anti-TNF) therapies related to rheumatoid arthritis treatment and satisfaction with information received prior to starting therapy - *for consideration under joint MICRA/ Manchester Health and Social Care Team (Manchester City Council and Manchester Clinical Commissioning Groups) section- for Changing patterns of demand for health and care services within ageing BME communities and how best to engage older BME communities in health promotion*

**AIM:** to explore the perceptions of ageing South Asian patients towards information received when starting on biologics and anti-TNF medication. This information will be used to develop patient centred content (template) for an audio CD.

**Co-applicants:** The project has a steering committee that includes the following staff and patient user involvement. Dr Kanta Kumar is an early career researcher/lecturer in Nursing at the University of Manchester. Her work in ethnicity has been published in high impact rheumatology journals<sup>1-6</sup> and she has vast experience working with South Asian patients<sup>1-6</sup>. She has national reputation for her work in ethnicity and has presented at many national rheumatology conferences like British Society of Rheumatology and the European League Against Rheumatism. She has experience of developing educational material and frameworks to support the care of South Asian population<sup>7</sup>. Her work has been highlighted as an excellent example in the National Audit Office Report for RA patients. The team will seek guidance on future stages of the project from Professor Ade Adebajo, Professor of Rheumatology, University of Sheffield. He has been awarded grants from Arthritis Research UK to develop educational material for South Asian patients. We have actively engaged with National Rheumatoid Arthritis (NRAS) with whom Dr Kanta Kumar has developed a designated project to engage South Asian patients. [www.nras.org.uk/apnijung](http://www.nras.org.uk/apnijung). NRAS will assist in disseminating the audio CD to a wider audience through [www.nras.org.uk/apnijung](http://www.nras.org.uk/apnijung). This website is given to family members in clinics to help engage patients in RA literature.

Dr Sabrina Raizada, Consultant Rheumatologist, The Royal Wolverhampton NHS Trust, Wolverhampton is situated in an area that serves a large proportion of South Asian patients and she has experience of investigating and improving clinical outcomes in rheumatoid arthritis patients. Dr Rebecca Stack, Senior Lecturer in psychology, Nottingham Trent University. Dr Stack is an experienced Health Service Research Psychologist. Dr Stack has developed patient reported tools and frameworks to improve patient care. Miss Shanali Perera, patient user, is from South Asian background with experience of being prescribed biologics. Miss Perera will bring her experience as a patient to the study, she will also contribute cultural understandings to the development of the interview schedule and interpretation of findings.

**Project background and justification:** Rheumatoid Arthritis (RA) is a condition with no cure and can cause disability<sup>8</sup>. RA affects nearly 1 in 100 adults. Early disease is characterised by pain and other features of inflammation, such as heat, swelling of joints, and loss of function. RA costs the NHS in England around 560 million a year, with increased costs in co-morbid conditions (such as cardiovascular (CVD) associated with RA<sup>9</sup>. CVD associated with RA is the most common cause of death in RA patients. The risk of developing CVD is worse in ageing South Asian RA patients<sup>10</sup>. Furthermore, RA causes physical damage and social, economic, psychological and cultural problems that impact on all aspects of patient life.

There are effective treatments available for RA<sup>11</sup>; however, non-adherence to medicines (not taking medicines as prescribed) is a significant issue in RA<sup>12</sup>. Patients' perceptions play an important role in adherence to medicines. Our research has showed differences between individuals from ethnic groups on how they view their medicines<sup>6</sup>. These views can potentially impact on medication adherence and patients' satisfaction with information they receive in clinic.

We have recently shown that South Asian patients with RA were dissatisfied with the information they receive about medicines<sup>6</sup> especially in second generation non-English speaking patients. Patients beliefs about medicines and illness perceptions were found to be associated with satisfaction with information received by clinicians. Furthermore, the British Society of Rheumatology (BSR) led a national audit to survey the delivery of care across UK rheumatology services. In this survey, we found that South Asian patients express greater impact of the disease on functional disability, fatigue, emotional well-being, physical well-being and coping and worse in older patients. This can impact on the way patients perceive their disease activity and information received on biologics. Biologics treatments in RA are costly and we need to take into account the decisions patients make about these treatments. While there has been much work relating to patient preferences towards receiving information in the general population about these medicines; there is little that relates directly to ageing South Asian patients. About 56% of women from ethnic background report suffering from a long term condition in Manchester. Manchester has a diverse ethnic population with many reporting poorer health outcomes. One of the aims of Manchester council is to reduce the inequalities in health reported by patients from ethnic backgrounds. In rheumatology practice, if we understand the needs of the South Asian patients better in clinic we can help improve the health outcomes. This project will give us some insight into what type of information is needed in clinics for South Asian patients in order to improve satisfaction with information and adherence. The data collected through this project will help us to develop a template for an audio CD that can be listened to by patients to achieve better understanding of disease and treatments.

#### Reference List

- (1) Kumar K, Gordon C, Toescu V, Buckley CD, Horn R, Nightingale PG et al. Beliefs about medicines in patients with RA and SLE: a comparison between patients of South Asian and White British origin. *Rheumatology* 2008; 47 (5):690-697.

- (2) Kumar K, Chambers S, Gordon C. Challenges of ethnicity in SLE. *Best Pract Res Clin Rheumatol* 2009; 23(4):549-561.
- (3) Kumar K, Daley E, Carruthers DM, Situnayake D, Gordon C, Grindulis K et al. Delay in presentation to primary care physicians is the main reason why patients with rheumatoid arthritis are seen late by rheumatologists. *Rheumatology (Oxford)* 2007; 46(9):1438-1440.
- (4) Kumar K, Daley E, Khattak F, Buckley CD, Raza K. The influence of ethnicity on the extent of, and reasons underlying, delay in general practitioner consultation in patients with RA. *Rheumatology* 2010; 49(5):1005-1012.
- (5) Kumar K, John H, Gordhan C, Situnayake D, Raza K, Bacon PA. Breaking communication barriers for RA patients of South Asian origin: the use of a bilingual educational audio CD and linguistically appropriate peer support and education. *Musculoskeletal Care* 2011; 9(1):11-18.
- (6) Kumar K, Raza K, Nightingale P, Horne R, Chapman S, Greenfield S et al. Determinants of adherence to disease modifying anti-rheumatic drugs in White British and South Asian patients with rheumatoid arthritis: a cross sectional study. *BMC Musculoskelet Disord* 2015; 16(1):396.
- (7) Kumar K, Deeming A, Gordon C, Nightingale P, Raza K. Experience with a Punjabi, Urdu and Hindi Rheumatology telephone helpline. *Musculoskeletal Care* 2008.
- (8) Emery P. Treatment of rheumatoid arthritis. *BMJ*; 2006; 152-155.
- (9) John H, Kitas G, Toms T, Goodson N. Cardiovascular co-morbidity in early rheumatoid arthritis. *Best Pract Res Clin Rheumatol* 2009; 23(1):71-82.
- (10) Grover S, Sinha RP, Singh U, Tewari S, Aggarwal A, Misra R. Subclinical atherosclerosis in rheumatoid arthritis in India. *J Rheumatol* 2006; 33(2):244-247.
- (11) Smolen JS, Landewe R, Breedveld FC, Buch M, Burmester G, Dougados M et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2013 update. *Ann Rheum Dis* 2014; 73(3):492-509.
- (12) Pasma A, Schenk CV, Timman R, Busschbach J, van den bemt B, Molenaar E et al. Non-adherence to disease-modifying antirheumatic drugs is associated with higher disease activity in early arthritis patients in the first year of the disease. *Arthritis Research & Therapy* 2015; 17:doi:10.1186/s13075-015-0801-4.