Institution: University of Birmingham

Unit of Assessment: A1

Reducing delays in accessing care for patients with a new onset of rheumatoid arthritis

1. Summary of the impact

Rheumatoid arthritis (RA) is a common destructive joint disease, causing pain and swelling, affecting 1 in 100 people. Work conducted by the University of Birmingham's Rheumatology Research Group has shown that early diagnosis is important, as the first few months represent a critical therapeutic window during which treatment can significantly improve health outcomes, increasing the chances of achieving disease remission and reducing the rate of progressive joint damage. The group have demonstrated that there are significant delays in patients making initial contact with their GP, which leads to delays in referral to a Rheumatologist and starting treatment; this situation has been shown to be worse in patients of South Asian origin. The outcome of the work has been incorporated into national policy documents and clinical guidance material and has underpinned a patient focused campaign to raise awareness of the disease and the need for early diagnosis.

2. Underpinning research

The work described in this case study was conducted by the Rheumatology Research Group, in the School of Immunity and Infection at the University of Birmingham, within their research strand focussed on management pathways for patients with new onset RA. The work was led by Professor Karim Raza (Professor of Clinical Rheumatology, at UoB from 2004) with support from clinical colleagues: Professor Chris Buckley (Arthritis Research UK Professor of Rheumatology, at UoB from 1996) and Dr Andrew Filer (Clinical Senior Lecturer in Rheumatology, at UoB from 2006). Qualitative aspects were supported by Ms Kanta Kumar (NIHR Doctoral Research Fellow, UoB from 2009), Dr Rebecca Stack (Postdoctoral Researcher, UoB from 2010) and Dr Karen Shaw (Birmingham Research Fellow, UoB from 2005); Kanta Kumar led aspects of the work focussed on access to care for patients from South Asian backgrounds. This case study is underpinned by primary research in three areas:

The importance of treating RA early:

The first few months of clinical disease represent a therapeutic window during which intervention leads to significantly improved outcomes, increasing the chances of achieving remission and reducing the rate of progression of joint damage (1). Work conducted in 2009 and 2010 by the Rheumatology Group in Birmingham, in collaboration with the University of Leiden, has contributed to a body of international data showing that early treatment, within the first 12 weeks of the onset of clinically apparent symptoms, is associated with a reduced rate of damage to bone and cartilage in the joint, therefore highlighting the benefit of early treatment of RA (1).

Identifying the problem: reasons why many patients with RA are treated late in the UK:

Whilst treatment within the first 12 weeks is associated with optimal outcomes, research conducted by the same group in Birmingham between 2004 and 2010 has shown that the median delay in access to specialist care where treatment is initiated is 23 weeks. The work has highlighted that, in the UK, the majority of the delay in getting to see a Rheumatologist and starting treatment is due to delay on the part of the patient in making an initial appointment to see their GP, with the median delay being 12 weeks. Delays on the part of GPs in referring, and on the part of Rheumatologists in seeing patients once a referral has been received, are shorter (2-4). Furthermore, the patient delay was significantly longer (24 weeks) in patients of South Asian origin (4). A parallel international study led by Prof Raza at the University of Birmingham within the EU funded AutoCure consortium (www.autocure.org), showed that delays at the level of the patient were also important contributors to total delay in assessment in a number of other European countries including Sweden, Switzerland and the Czech Republic (3).

Informing the solution: approaches to reducing patient delay in the UK:

In order to reduce patient delay, the reasons underlying it need to be understood. The same group in Birmingham have carried out primary qualitative work to attempt to understand why patients delay in making contact with their GP (4). In addition, as part of a National Institute for Health Research (NIHR) funded Research for Patient Benefit grant (Chief Investigator Prof Karim Raza; Reference number PB-PG-1208-18114 "Help seeking behaviour in patients with new onset rheumatoid arthritis: understanding the reasons for delay in GP consultation and strategies to reduce this delay". 2010-13) the group has conducted a synthesis of the qualitative literature in relation to reasons for delays in help seeking in patients with inflammatory arthritis (6). Results showed a lack of awareness that symptoms of inflammatory arthritis might indicate a serious disease for which effective treatment was available, that most patients initially attributed joint symptoms to "normal wear and tear", and that most patients thought, at symptom onset, that they were too young to develop arthritis.

3. References to the research (indicative maximum of six references)

Authors from the University of Birmingham are highlighted in bold:

1. van der Linden,M.P., le Cessie,S., **Raza,K**., van der Woude,D., Knevel,R., Huizinga,T.W., and van der Helm-van Mil AH Long-term impact of delay in assessment of patients with early arthritis. *Arthritis Rheum* 2010; 62 :3537-3546. *DOI 10.1002/art.27692*

2. **Kumar,K**., Daley,E., Carruthers,D.M., Situnayake,D., **Gordon,C**., Grindulis,K., **Buckley,C.D**., Khattak,F., and **Raza,K**. Delay in presentation to primary care physicians is the main reason why patients with rheumatoid arthritis are seen late by rheumatologists. *Rheumatology (Oxford)* 2007; 46:1438-1440. *DOI 10.1093/rheumatology/kem130*

3. **Raza,K**., **Stack,R., Kumar,K**., **Filer,A**., Detert,J., Bastian,H., Burmester,G.R., Sidiropoulos,P., Kteniadaki,E., Repa,A., Saxne,T., Turesson,C., Mann,H., Vencovsky,J., Catrina,A., Chatzidionysiou,A., Hensvold,A., Rantapaa-Dahlqvist,S., Binder,A., Machold,K., Kwiakowska,B., Ciurea,A., Tamborrini,G., Kyburz,D., and **Buckley,C.D**. Delays in assessment of patients with rheumatoid arthritis: variations across Europe. *Ann Rheum Dis* 2011; 70 :1822-1825. *DOI 10.1136/ard.2011.151902 (in REF2)*

4. **Kumar,K**., Daley,E., Khattak,F., **Buckley,C.D**., and **Raza,K**. The influence of ethnicity on the extent of, and reasons underlying, delay in general practitioner consultation in patients with RA. *Rheumatology (Oxford)* 2010; 49 :1005-1012. *DOI 10.1093/rheumatology/keq011*

5. Sheppard,J., **Kumar,K., Buckley, C.D., Shaw, K,L,, Raza, K**. "I just thought it was normal aches and pains": A Qualitative Study of Decision Making Processes in Patients with Early Rheumatoid Arthritis. *Rheumatology (Oxford)* 2008; 47:1577-82. *DOI 10.1002/art.23681*

6. **Stack,R.J., Shaw,K**., Mallen,C., Herron-Marx,S., Horne,R., and **Raza,K**. Delays in help seeking at the onset of the symptoms of rheumatoid arthritis: a systematic synthesis of qualitative literature. *Ann Rheum Dis* 2012; 71:493-497. *DOI 10.1136/ard2011.155416*

4. Details of the impact

The work to reduce delays in access to care for patients with RA has had impacts in the fields of **public policy and services** as well as **health and welfare**.

Public policy and services - policy debate has been stimulated and moved forward by research evidence:

The work, highlighting that patient delay in accessing GPs is a major contributor to overall delays in the assessment of patients with a new onset of RA, informed the 2009 report by the National Audit Office on "Services for people with RA", which has highlighted the need to reduce delays in help seeking behaviour on the part of patients and the subsequent impact on the economy through patients being able to remain in the UK workforce. The report highlights the following: "*Too many people with rheumatoid arthritis are not presenting, or being diagnosed and treated quickly enough. Better value for money could be achieved through increasing the number of people diagnosed within three months of onset of disease. Our modelling work suggests that increasing from 10 to 20 per cent the number of people treated within three months would initially increase overall NHS costs by £11 million over the first five years; but would improve people's quality of life and for the proportion that are of working age, earlier treatment would improve their chances of remaining in work, generating productivity gains for the economy of around £31 million. After around nine years, earlier treatment could become cost neutral to the NHS, with ongoing benefits of: improved quality of* *life; and reduced demands on the NHS (for example for surgery)*" (1).

This report was highly influential in informing national policy. Following its publication and prior to meeting with the Committee of Public accounts, the then Chief Medical Office (David Nicholson) met with Prof Karim Raza in Birmingham (18th November 2009) to discuss issues related to patient delay. In answer to the following question from the Chairman of the Committee of Public accounts "*Presumably you have no trouble, Mr Nicholson, with recommendation (a), paragraph 18 on page nine: "The Department of Health should explore the cost-effectiveness of options for raising public awareness of the symptoms of inflammatory arthritis, including rheumatoid arthritis, to encourage people to present to the NHS promptly after symptom onset.""* David Nicholson replied *"I think it is absolutely the right thing to do ...We are considering, I think quite actively at the moment, a bid from Birmingham, as it happens, for research into the area of public awareness so we can absolutely focus our attention on things that will work"* (2).

The bid referred to by David Nicholson was funded by the NIHR under the Research for Patient Benefit Scheme (Chief Investigator Prof Karim Raza; Reference number PB-PG-1208-18114) and was supported by Arthritis Research UK, the National Rheumatoid Arthritis Society (NRAS) and the Arthritis and Musculoskeletal Alliance (ARMA).

Health and welfare - public awareness of a health risk or benefit has been raised:

The work on understanding the reasons why patients delay in seeking early help with their disease has informed the development of a public health campaign launched in 2011 by the National Rheumatoid Arthritis Society to reduce delays on the part of patients (3). This campaign highlighted that the typical symptoms of early RA (stiffness, swelling and tenderness) might be an indication of a disease for which urgent treatment was necessary. In part, the NIHR funded study, referred to above, will be a assessing the impact of this campaign and will look at ways of enhancing the effectiveness of future public health messages.

One of the key issues that this work has identified is that patients of South Asian origin are more likely to delay in seeking help compared with the general population. Recognising this, the Rheumatology Research group has worked with the Birmingham Arthritis Resource Centre (BARC) to develop strategies to raise awareness amongst members of ethnic minority groups (4). BARC is a voluntary organisation based in Birmingham Central Library and supported by the University of Birmingham and Birmingham City Council. Strategies developed with BARC have included audio information on a range of topics including "understanding arthritis", available as a bilingual CD and as an audio file (5), running outreach sessions in local community venues (e.g. temples), appearing on local South Asian radio stations to talk about RA and writing articles about RA for South Asian language magazines. The effectiveness of the BARC audio CD has been demonstrated in a study published in Musculoskeletal Care in 2011 (6). All patients who participated in the study confirmed that the CD had been a useful source of information and had addressed some of the language barriers which they had previously experienced. In 2011 the University's work with BARC in the community was awarded the 2011 Nursing Standard award for Innovations in Rheumatology (7). Furthermore the work has attracted considerable media attention, which has helped to raise awareness of the disease and the need for early diagnosis.

5. Sources to corroborate the impact

1. National Audit Office Report "Services for people with RA" published 15th July 2009: http://www.nao.org.uk/publications/0809/rheumatoid_arthritis.aspx.

2. Transcript of the Chief Medical Office answering questions from the committee of public accounts published 23rd February 2010: http://www.publications.parliament.uk/pa/cm200910/cmselect/cmpubacc/46/46.pdf.

3. National Rheumatoid Arthritis Society campaign to promote rapid help seeking for RA, campaign launched 11th November 2011: http://nras.org.uk/about_rheumatoid_arthritis/what_is_ra/how_is_it_diagnosed/have_you_got_s_factor.aspx.

4. Birmingham Arthritis Resource Centre: http://www.barc.org.uk/.

5. Birmingham Arthritis Resource Centre information on “understanding arthritis” available as an audio file: http://www.barc.org.uk/media/index.html.

6. **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;9:11-8. *DOI 10.1002/msc.191*

7. 2011 Nursing Standard award for Innovations in Rheumatology: adverts showing finalists and copy of Nursing Standard confirming award.

8. The *Financial Times* ‘Early care urged for rheumatoid arthritis’: http://www.ft.com/cms/s/2/1d847d3a-c0d7-11df-94f9-00144feab49a.html#axzz2Kwk6TtHe.

9. The *Guardian* ‘Failure to act on early signs of rheumatoid arthritis could prove fatal’: http://www.guardian.co.uk/science/2010/sep/15/early-signs-rheumatoid-arthritis.