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Rheumatoid arthritis patients face unofficial postcode lottery for treatment: survey reveals widespread contravention of government policy and NICE guidance

People suffering from the debilitating pain of rheumatoid arthritis (RA) face a postcode lottery over whether they can have access to a treatment that is known to improve their condition significantly.

New research published in the medical journal *Rheumatology* [1] today (11 October 2006) reveals that, despite the National Institute for Health and Clinical Excellence (NICE) approving anti-tumour necrosis factor *alpha* (TNF) therapy for RA in 2002, many primary care trusts are refusing to fund it adequately or are putting a cap on the numbers of patients that can be treated.

The picture is even worse for the use of anti-TNF therapy in other arthritic conditions such as psoriatic arthritis (PsA) and ankylosing spondylitis (AS) where NICE approval has only just been given or is being awaited.

As a result of these findings, rheumatologists are calling on the Government and primary care trusts to end the unofficial postcode lottery and ensure that every patient who meets the NICE criteria can receive anti-TNF therapy if their consultants consider it appropriate.

Dr Lesley Kay, a member of the British Society for Rheumatology Biologics Register (BSRBR) management committee and co-author of the research, said: "The BSRBR urges the Government and primary care trusts to put an end to this patently unfair situation, which is in direct contravention of government policy. The postcode lottery continues to operate, even though NICE aims to stop this happening. It's unfair on patients with these devastating, painful and unglamorous conditions to be forced to take a low priority and to be deprived of this very successful treatment."

Randomised clinical trials have shown anti-TNF therapy is highly effective in the treatment of RA, juvenile idiopathic arthritis (JIA), PsA and AS. Not only can it arrest the progress of the disease, preventing deformity, but also patients report considerable improvements in symptoms such as joint pain, swelling, mobility and fatigue, and often say that the treatment has made them feel well in themselves for the first time in many years. [2]

However, when Dr Kay and Dr Ian Griffiths sent questionnaires on behalf of the BSRBR (which monitors the use of anti-TNF therapy) to 509 consultant rheumatologists in the UK, the responses on behalf of 252 consultants revealed a wide disparity in the provision of anti-TNF therapy across the country.

Dr Kay, a consultant rheumatologist at the Freeman Hospital and Newcastle University, Newcastle upon Tyne, UK, said: "Nearly half of the consultants (46%) indicated that they had some form of limitation in their prescribing of anti-TNF

agents for RA according to NICE guidance. Of these, 70% said these limitations were mainly in the form of capped funding or capped numbers of patients; staffing or lack of other facilities was a problem for 21% and 9% respectively.

"The consultants said they faced problems such as a fixed number of patients that they were allowed to treat each month, fixed financial caps, bans on treating any more patients until the next financial year, and the fact that different primary care trusts had different financial limits. Waiting lists were also a means of controlling access to treatment, with some patients waiting as long as 156 weeks."

For PsA, for which anti-TNF therapy received NICE approval in June 2006 after the survey had been completed, and AS, for which NICE is expected to issue guidance in 2007, the situation is even worse.

"Only 67% of consultants have any access to anti-TNF therapy for patients with PsA or AS, whilst their ability to prescribe according to the British Society for Rheumatologists' guidance is limited to 25% for AS and 30% for PsA," said Dr Kay.

"The fact that different funding organisations set different restrictions has led to variation of access for equally affected patients to effective treatment, depending on where they live. The survey was anonymous, so we cannot use our data to map the disparity in provision across the country."

Dr Kay said this disparity in the provision of a treatment, which could change the lives of RA patients, inflicted great mental and physical pain on them, and she described the human suffering behind the figures.

"I often put it to patients that if you wanted to design torture for someone, you'd give them pain, uncertainty about what the next day and the future would be like (inflammatory arthritis varies enormously from day to day and from patient to patient so you can never plan anything and your friends and family start to think you are unreliable), deprive them of sleep (arthritis is usually at its worst during the night and first thing in the morning), and threaten their independence and their ability to earn money and look after their families. Then you'd add to it by saying that there are these drugs that could put it all right for many people, but you can't have them because somebody thinks they cost too much."

She also urged NICE to issue guidance on anti-TNF therapy for AS as quickly as possible. "AS patients are in a difficult situation as there is really nothing else, apart from non-steroidal anti-inflammatories (NSAIDs), that helps, and these are known to have serious possible side-effects such as heart attacks and strokes, stomach ulcers, perforations and gastrointestinal bleeds. Conditions like AS don't get the publicity or sympathy that cancer does – look how fast Herceptin was processed – but it causes lifelong disability in patients who are typically young men."

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[1] "UK consultant rheumatologists' access to biologic agents and views on the BSR Biologics Register" by L.J. Kay and I.D. Griffiths. *Rheumatology Advance Access* published on 11 October, 2006. doi: 10.1093/rheumatology/kel333

[2] "Patients' perceptions of treatment with anti-TNF therapy for rheumatoid arthritis: a qualitative study" by N.J. Marshall, G. Wilson, K. Lapworth and L.J. Kay. *Rheumatology* 2004; 1034-1038.

[3] Rheumatoid arthritis affects three times as many women as men. Prevalence in the UK is approximately 0.5% in men and 1.8% in women, increasing after the age of 64 to 2% in men and 5% in women. There are many more people with less severe forms of RA that do not meet the diagnostic criteria for definite or classical disease.

[4] Anti-TNF therapies include etanercept and infliximab. NICE has approved both for the treatment of RA, and etanercept for JIA only. Anti-TNF therapy works by targeting circulating TNF alpha (a regulatory protein, released by the cells of the immune system, that controls generation of the immune response) and preventing it from activating the pathways in the immune system that lead to inflammation.

Notes:

1. A PDF of the full embargoed text of the paper can be found from 10.00 hrs London time on Monday 9 October 2006 at:

www.oxfordjournals.org/our_journals/brheum/press_releases/freepdf/kel333.pdf

The pdf is also available from Mithu Mukherjee, OUP. Email: mithu.mukherjee@oxfordjournals.org or tel: +44 (0)1865 354471.

A PDF version of this press release can be found at:

www.oxfordjournals.org/our_journals/brheum/press_releases/oct06.pdf

2. The paper will be published online on Wednesday 11 October 2006 at:

<http://rheumatology.oxfordjournals.org/papbyrecent.dtl>

The *Rheumatology* journal website is: www.rheumatology.oxfordjournals.org

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3. *Rheumatology* is the official monthly journal of the British Society for Rheumatology (BSR).

The BSR website is: <http://www.rheumatology.org.uk/>