

James Lind Alliance Meeting, 3 December 2005 - Taking patients' and clinicians' questions seriously about the effects of treatment seriously.

Abstract - Professor John Kirwan and Enid Quest

Rheumatoid arthritis – What have we found and what are we trying to do about it?

Rheumatoid arthritis is a nasty disease. It affects people of all ages, causing severe pain, stiffness and disability. Symptoms vary unpredictably from day to day and week to week. 25% of patients give up work within a year and another 25% within a few years. About 10% of patients become functionally dependant on others within 10 years. Treatment is complicated, includes physical therapies, coping mechanisms and medication, and has to be tailored to individual patients. There are many pharmaceutical company interests tied up in the medications available.

An international movement of clinicians and methodologists called OMERACT (outcome measures for rheumatology clinical trials) was formed 14 years ago, and successfully standardised a 'core set' of outcome measures for rheumatoid arthritis clinical trials, which has been adopted by the regulatory agencies. When patients themselves were invited to join OMERACT in 2002 it became clear that there was a mismatch between the views of the research community and patients' needs and expectations (1). We will describe how researchers and patients responded to this, and what we are trying to do about it (2, 3).

1. Kirwan J, Heiberg T, Hewlett S, Hughes R, Kvien T, Ahlmèn M, Boers M, Minnock P, Saag K, Shea B, Suarez Almazor M, Taal E. Outcomes from the Patient Perspective workshop at OMERACT 6. *J Rheumatol* 2003; 30: 868-72.

2. Kirwan JR, Hewlett S, Heiberg T, Hughes R, Carr M, Hehir M, Kvein T, Minnock P, Newman S, Quest EM, Taal E, Wale J. Incorporating the patient perspective into outcome assessment in rheumatoid arthritis – progress at OMERACT 7. *J Rheumatol* 2005; 32: 2250–6.

3. Hewlett S, De Wit M, Richards P, Quest E, Hughes R, Heiberg T, Kirwan J. Patients and Professionals as Research Partners: Challenges, practicalities and benefits. *Arthritis Care & Research (Arthritis & Rheumatism)*; In press.