
Should patients tell researchers what to do? If so, how?

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JOHN KIRWAN

CASE STUDIES: PATIENT INVOLVEMENT IN RHEUMATOID ARTHRITIS RESEARCH
JOINT PRESENTATION WITH PAM RICHARDS



BIOGRAPHY

John Kirwan is Professor of Rheumatic Diseases at the University of Bristol and Consultant Rheumatologist at Bristol Royal Infirmary. He has been an active member of Outcome Measures in Rheumatology Clinical Trials (OMERACT), the international consensus group, where for the last 5 years he has had the responsibility of introducing patient participation into OMERACT activities. His research interests include long term outcome and disease mechanisms in osteoarthritis and rheumatoid arthritis, and the delivery of patient-centred health services.

RELEVANT COMPETING INTERESTS

None

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PAM RICHARDS

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JOINT PRESENTATION WITH JOHN KIRWAN
PANEL DISCUSSION



BIOGRAPHY

Pam Richards has worked primarily with the Rheumatology Department of the University of Bristol as a Research Partner on a number of local and international project steering groups. Drawing on her experiences, she acts as an advisor on patient participation and also helps support the team of Research Partners based in Bristol. She is current chair of Outcome Measures in Rheumatology Clinical Trials (OMERACT - the international research organisation) patient panel.

ABSTRACT

Including the patient's perspective in research is becoming the norm within the Rheumatology Departments of the Bristol Royal Infirmary, the University of Bristol and the University of the West of England, Bristol. Experiential knowledge is treated as a valuable resource and included at all stages of the research process. Patient Research Partners work alongside clinicians and researchers to ensure projects are relevant and based around patients' priorities.

We will outline a local (Bristol) and an international ⁽¹⁾ example of patient involvement in arthritis research, based on a similar collaborative model of interaction between patients, clinicians and researchers. From these we have drawn conclusions about successful integration.⁽²⁾

In describing these models we will illustrate how collaboration not only benefits research but also has a direct impact on local service delivery. A good example of patients driving the international research agenda is that of fatigue in rheumatoid arthritis, a field which has been pursued as a direct result of patient participation in an OMERACT conference.⁽³⁾

Supporting patients who make a commitment as research partners is essential, as is supporting researchers seeking to include the patients' perspective and we will briefly mention how we have endeavoured to achieve that.

- 1 Quest E. Patients' Perspective. J Rheumatol 2003; 30: 884-5.
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- 3 Kirwan J, Minnock P, Adebajo A, Bresnihan B, Choy E, De Witt M, Hazes M, Richards P, Saag K, Suarez-Almazor M, Wells G, Hewlett S. Patient Perspective Workshop: Fatigue as a recommended patient-centred outcome measure in rheumatoid arthritis. J Rheumatol 2007; 34: 1174-77.

RELEVANT COMPETING INTERESTS

None

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