

Raising the profile of arthritis and musculoskeletal conditions

Ros Meek speaks to Shreeya Nanda, Commissioning Editor

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ARMA, Bride House, 18–20 Bride Lane, London, EC4Y 8EE, UK ■ Tel.: +44 207 842 0910
■ rosmeek@arma.uk.net



Ros Meek is the Director of the Arthritis and Musculoskeletal Alliance (ARMA). She took over from Steve Milton, the interim Director, earlier this year. Ros has trained as a nurse, worked in professional bodies such as the Community Practitioners' and Health Visitors' Association (CPHVA) and Royal College of Nursing on primary care policy and nursing development, and latterly managed Government Affairs at Wyeth Pharmaceuticals.

■ What are the aims of the Arthritis and Musculoskeletal Alliance?

The Arthritis and Musculoskeletal Alliance (ARMA) is the umbrella body for the arthritis and musculoskeletal community in the UK and is a registered charity. ARMA brings together an alliance of 33 different national service user organizations, professional associations and research bodies, all working in the field of arthritis and other musculoskeletal conditions.

Together, ARMA and its member organizations work to improve quality of life for people across the UK with musculoskeletal conditions (TABLE 1).

As an umbrella body, ARMA works with and through its membership, bringing member organizations together to work collaboratively towards common goals and joint initiatives. ARMA is fully committed to the user-centered approach to service development, and has a strong track record of user involvement in all its activities and structures.

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■ Can you tell me about the projects implemented by ARMA?

ARMA has brought its members together to create 40 local networks, which link into the local primary care trusts. They are a ready source of information regarding local issues, and are keen to get involved as necessary in service redesign and innovation.

ARMA has produced seven Standards of Care documents with associated audits, which are available on their website [1]. These cover

Inflammatory Arthritis, Osteoarthritis, Connective Tissue Diseases, Regional Musculoskeletal Pain, Back Pain, Metabolic Bone Disease and Musculoskeletal Foot Health.

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■ What does your current work at ARMA involve?

ARMA has a network of 40 local groups that are comprised of people from our local membership, people living with the condition, clinicians, allied health professionals and researchers. These groups work with the local health economy to redefine service specifications and to advise on service redesign. We are currently in the early stages of working on creating *Standards of Care for Juvenile Idiopathic Arthritis* with the British Society for Paediatric and Adolescent Rheumatology (BSPAR). We are reviewing the other Standards of Care documents that we have produced on *Inflammatory Arthritis, Osteoarthritis, Connective Tissue Diseases, Metabolic Bone Disease, Back Pain, Regional Musculoskeletal Pain* and the associated audits. In addition, we recently launched the *Musculoskeletal Foot Health Standards of Care*. We are about to start work reviewing the progress of the Musculoskeletal Services Framework document that was launched by the Department of Health in 2006. The National Audit Office Enquiry into Rheumatoid Arthritis is also involving our membership, and is reviewing services for people with rheumatoid arthritis (RA) of working age. Much of our work centers around the health technology appraisals undertaken by NICE.

Table 1. Four core ARMA objectives.

Policy and profile	Leading the community in influencing the development of policies that affect people with musculoskeletal conditions and raising the profile of these conditions with policy-makers
Practice	Developing and promoting guidance and good practice on improving standards of care for people with musculoskeletal conditions
Partnership and participation	Fostering the development of networks in which representatives of member organizations can work in partnership to influence policy and service development
Fit for purpose	Ensuring that ARMA has a diverse and secure funding base that enables the organization to grow in capacity in order to deliver its plan more effectively

ARMA: Arthritis and Musculoskeletal Alliance.

ARMA provides input into NICE on behalf of its membership

■ **Could you briefly describe the recently published NICE appraisal document on sequential treatment for rheumatoid arthritis?**

NICE recently produced its final appraisal document (the last stage before its official guidance) on the use of three anti-TNF drugs for treating RA. This appraisal looked at the clinical- and cost-effectiveness of using anti-TNFs in sequence, for example, switching to a second (or third) anti-TNF if the first was poorly tolerated or had become ineffective. NICE concluded that additional anti-TNF treatment should not be used where a previous treatment had failed – except in the context of clinical trials. They stated that to do so would be an inappropriate use of National Health Service (NHS) resources. This decision comes despite ARMA and other organizations providing evidence to the contrary, and the fact that there are significant wider societal costs incurred by someone with severe RA disease. For example, over a quarter of people with RA have to stop working within a year of diagnosis, and up to half of people with RA are unable to work and apply for disability benefits within 10 years of diagnosis. ARMA is appealing the decision.

■ **What is the basis for this recommendation by NICE?**

This NICE decision comes despite these drugs not being brand new, and there already being the acknowledgement that each anti-TNF treatment is individually clinically and cost-effective. NICE claims to have examined the evidence and sought opinions from patients. However, we would contest both the involvement of patients in producing the guidance, and the clinical- and cost-effectiveness data NICE has focused on, which form the basis of its decision. For example, wrongly in our view, NICE is not permitted to take account of wider costs of this progressive disease, for example carer costs, and they also failed to include the shortage of other treatment options for patients

who fail on their first anti-TNF. There is strong evidence that shows that thousands of people will be forced out of work and possibly onto benefits as a result of their severe RA symptoms being untreated. It is unfortunate that NICE do not take these costs into account, and is on the path of actually limiting existing practice.

■ **What are the implications for patients?**

The implications of the appeal being turned down by NICE on sequential use of anti-TNF is that unless patients are taking part in a research trial, they will be unable to switch from one anti-TNF to another if the medication fails. It is not uncommon that patients switch from one product to another and find relief from their symptoms. Ultimately, it will mean that unless research trials are undertaken, these people will effectively be left in pain and with increasing disability, which ultimately may cause them to have to give up work and depend on benefits.

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■ **Where will the efforts of ARMA be focused over the next 5 or 10 years?**

Musculoskeletal conditions are the most common reason for repeat consultations with the GP, comprising up to 30% of primary care appointments. These people are the second largest group (22%) receiving incapacity benefits. It has been recognized that such patients have often not received the care and support required for their conditions. We will be working to raise the cause of these people who are often diagnosed early on in their life and have to live with the disease. Biomedical research is yielding many technological advances offering new ways to diagnose and treat musculoskeletal conditions, including the development of improved prostheses for joint replacement,

improved diagnostics and drug therapies, and the introduction of self-management. ARMA has the unique advantage of being able to represent clinicians, allied health professionals and those living with the condition, and is thus well placed as the Darzi recommendations come into fruition on a local basis, to engage with local management of primary care trusts to review and improve on the services, making them more user-focused and responsive to their needs.

Financial & competing interests disclosure

Ros Meek has stock options as a result of former employment by Wyeth Pharmaceuticals. The author has no other relevant affiliations or financial involvement with any organization or entity with a financial

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<http://arma.uk.net>

Affiliation

- Ros Meek
ARMA, Bride House, 18–20 Bride Lane, London,
EC4Y 8EE, UK
Tel.: +44 207 842 0910
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