

## Patients' Perspective

For the first time in its 10-year history, there was an extra body of people at the recent OMERACT 6 conference in Brisbane, consisting of 10 nervous, bewildered individuals with one thing in common, rheumatoid arthritis (RA). If there is one country where strangers can feel at ease, it is Australia, and so it was in this case.

The group of 10 started with an informal meeting and following the opening introductions they bonded easily and started to share their own experiences of RA. One thing that was immediately obvious were the different attitudes and methods that patients, primary care doctors, and rheumatologists employed when dealing with RA, each approach having its own positive aspects, with some perhaps more advanced than others. However, there were enough differences for everyone to realize that the medications and treatments for RA do not stand still and continue to advance to the benefit of the patients, simultaneously adding to the knowledge of the involved health care professionals.

Not all the talk among the patients was anecdotal. There were serious concerns raised as to how overdue patient involvement within OMERACT was: would we be listened to actively, or worse, be ignored by the experts? However, these concerns soon proved to be without foundation. The reception accorded the patients was extremely welcoming. There was a tangible feeling of relief and a belief that patients' views and opinions would be listened to and incorporated into the deliberations.

The patients in attendance included both men and women who had travelled from a wide selection of countries, including the UK, Sweden, Norway, The Netherlands, US, France, and from the host country Australia. There was a good mixture of ages, experiences, and social backgrounds. It was disappointing not to have patient representatives from more diverse cultures at this inaugural meeting with patients and clinical researchers.

The patient involvement at the conference was primarily through the Patient Perspective Workshop led Dr. John Kirwan, UK. This was in 3 parts — the preamble, the workshop, and the plenary. There was also the Minimal Clinically Important Differences Workshop led by Dr. George Wells, Canada. As part of the Patient Perspective Workshop there was an excellent speech entitled "Patients Count" by Shirley Collins, one of the Australian patients. We were later to learn that giving the talk on stage from her wheelchair had been an extremely daunting experience but, all credit to Shirley, the talk itself was both enlightening and thought provoking. The opening keynote speech was given by Amye Leong, a patient advocate with the Bone and Joint Decade, who reinforced to the entire group that in this decade we

each hold equal responsibility for moving forward to improve the quality of living for those affected by musculoskeletal disorders: two great examples of the valuable input patients can have at these events.

We agreed that there was a level of underestimation of the patient's role within the functioning of OMERACT. The discussions around the measurement of fatigue or the lack of ability to measure fatigue were intriguing. The patients shared the view that there should be a review of the current means of measuring both fatigue and stress for those with RA. It is accepted that the measurement of such subjective, and in many ways individual, experiences is extremely difficult, but it is so crucial to the overall approach to this disease that it is worth the extra investment of time and effort. Throughout the conference the concept of "well being" was frequently discussed. This is important to patients and is not usually referred to in any consultation.

A further task for the patients was to define "low disease activity state." In other words, what level of pain or inflammation and physical disability could we accept in order to feel that our RA was being kept under control?

Patients were concerned about the terms used within OMERACT. There is a tendency to use acronyms around the "core set," which caused some confusion. It was agreed there needs to be a new glossary that is simple, shared, direct, communicated, and understood by all.

Certain terminology used outside of OMERACT is important to patients and it was recognized by the range of experts that this needs to be worked into OMERACT processes in a way that is meaningful to patients. This will mean extending the measures and definitions within the current OMERACT framework.

There was an appreciation by the patients of the difficulties involved with the definition of terms and that this is a subjective process. However, we suggested there needs to be alignment and understanding between the patients and the physicians. Patients want to be considered as whole individuals whose lifestyle decisions can affect the course of their disease, not a collection of organs and body parts. This is an important paradox for patients and researchers and needs to be addressed.

Will the rheumatologists, statisticians, clinical researchers, nurses, etc., who attended the conference include patients in any relevant future meetings? We hope so, as we all felt that we could make a positive contribution to discussions about outcome measures for RA. We most definitely do have our own opinions and views and would like the proper platforms and venues to express them. It was a privilege to attend the conference. Meeting other patients and sharing experiences

was a bonus. We were encouraged by the response to our participation and hope that future OMERACT meetings will continue to involve patients.

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