



Ms Sue Oliver OBE

Past Chair of European League Against Rheumatism (EULAR)
Health Professionals in Rheumatology Standing Committee

1 After your master's in science, healthcare, and professional issues, what sparked your interest in Chairing the Royal College of Nursing (RCN) Rheumatology Forum?

When I started my masters, I think that I was always keen to have a role where I could make a bit of a difference and so finding a way to do that felt right for me. In 2002 and 2004 before I was Chair, I was a co-opted member of the Rheumatology Forum. The forum is for nurses who are interested and want to get actively involved; there was so much going on within the field of rheumatology and it was very exciting at the time. So, there were many reasons why I wanted to be more actively involved in the Rheumatology Forum; I felt specialist nurses needed to have more power, to be recognised more within the field, but also that we needed to step up and be more actively engaged in supporting patients through many aspects of care. I learned a lot about the Forum and the RCN and how professional aspects could be developed within the RCN, before being co-opted. I really love rheumatology and I found a place that fitted well for me. I went to the 1999 American College of Rheumatology (ACR) conference, but I also went to the pre-scientific meeting which is where all the breaking news was presented. I was very lucky that I went in the year that they were introducing biologics for the first time; sitting there and listening, I thought this was a huge revolution. There was a lot of interest in biologics in the UK but also many challenges to the nurse specialist because it was a new field and we were going to be managing these patients. Lots of nurses didn't know about how to screen and assess these patients. It was key to me that we had offered resources and support to nurses within the field of rheumatology.

2 What were the most important learnings from your clinical roles with the National Health Service (NHS) that led you to

be a successful consultant for various organisations such as the Department of Health, Kings Fund, National Audit Office, and the National Institute for Health and Care Excellence (NICE)?

I left the NHS and my clinical nurse specialist role after doing quite a lot of reading about the future and how nurses could develop, guiding my decision to set up my own clinic doing consultancy work. I had quite a lot of experience because I'd already served as the Chair of the Rheumatology Forum and started representing nurses in the Department of Health and the British Society for Rheumatology (BSR), as well as being Chief Nurse Advisor for the National Rheumatoid Arthritis Society and working on guidelines for NICE. I then set up my own consultancy after conducting a nurse prescribing course and running advanced nurse-led clinics. I really wanted to expand the role of the nurse, but also be a strong role model and really test some of the new ways of going forward. When you're in a clinic you're booked for 6 weeks in advance, but because I was independent, I was flexible and able to go to meetings. I gave my time freely and was lucky because my husband was very supportive. I gave a lot of my time and energy freely because I really felt there was a vision and a need that I really wanted to build on. At the core of me is an NHS nurse, and the more I've travelled around the world the more I think the NHS is the most fabulous healthcare system.

All of these were the reasons I got involved, with the overall aim of improving care for patients. I was representing patients by working with a patient organisation and they were saying "we don't see the doctors as often as it says in the guidelines" and "we don't get access to this/that." I spoke to the chief executive of the patient organisation and said we need to do something together; we need to try and understand what's happening in our services. We got a meeting together

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with rheumatologists at the BSR, the patient organisations, and also the pharmaceutical industry, because they're actually very well-informed, very able, and very interested in the services. So, we managed something that I didn't think could be achieved which is to get them all sitting around a table together and agreeing to work collaboratively. This was called the Futures Forum and as a result we managed to commission a piece of research that was undertaken by the Kings Fund. So to answer your question more clearly, each of these different pieces of work gave me a greater insight into how to get all parties to work together to try and identify barriers and identify ways to improve the patients' journey through healthcare. My real key learning was to focus on the patients' journey and how to optimise that journey in the most evidence based, cost effective way.

You have been especially committed to raising awareness of chronic conditions such as rheumatoid and osteoarthritis; what are the most common patient outcomes for these diseases and how can they be improved?

When people are diagnosed with a chronic condition the diagnosis has an effect on the patient's self-esteem and it can present a challenge. It's an unspoken agenda that often society sees people with chronic conditions as different, and some patients feel that they have failed in some way. It's a challenge they have to face, so I care very much about how the diagnosis is delivered and how health professionals help those patients come to terms with their condition. The manner in which you start the journey with a new patient is vital to how they will see themselves and go forward with their disease in the future. I think that it's not only an important investment in time but also for future well-being of the individual. I've been committed to chronic disease issues because as a healthcare professional we have historically been too paternalistic and fostered reliance on healthcare rather than independence. There are many ways to encourage independence, but we need to build them into what we will

deliver throughout the individual's healthcare journey. If we do that then the patient outcomes, I believe, should encompass aspects that demonstrate how empowered the individual feels,

their understanding of healthcare resources and how to access them, and better knowledge of treatments. Why should I expect the patient to just take something like methotrexate because I say it's beneficial? We have to take them gently on that journey, and the skill of the health professional is in understanding our patients by getting some sense of their anxieties and learning needs as quickly as possible, as well as working with them to achieve the best outcomes for them.

Could you tell us about the rheumatology nursing educational developments that you have been supporting in Asia?

I love the Asia-Pacific region, and 18 years ago I was approached by Professor Gavin Lee who was the president of the Rheumatology Society in Hong Kong. He invited me to visit and deliver lectures and speak to some senior rheumatologists about why they should consider developing rheumatology nursing. I was so impressed with them, but also aware of the challenges when I visited a hospital in Hong Kong. I was shocked at how difficult it was for them; the clinics were huge, and patients had so little time with the doctor. It was an impossible situation to continue operating that way forever and it was going to have to change. I was keen to help and keep in touch regarding their progress, so I offered general support in little ways such as mentoring and sending information, as a result of which I was invited back several times. We were trying to develop rheumatology nursing in Hong Kong so that it would be recognised as a specialty within the nursing authorities. Our first challenge was working within the framework that would work best for Hong Kong; you have to look at the organisation and professional challenges and work with their stipulations. The rheumatology services in Hong Kong have done a great job and rheumatology nursing has now been recognised as a nursing speciality; it is really well-defined and working smoothly. I am still in regular communication and actively enjoy supporting their development as and when need.

Q5 What impact do you hope your online resources for both healthcare professionals and patients to have?

It's been a good place for Asia-Pacific healthcare professionals to get some resources. For instance, there is the Royal College of Nursing disease activity score (DAS) video which has been translated into different languages such as Chinese etc. Chiefly, I want to sign post those interested to the latest evidence-based guidelines and to organisations that offer valuable resources, providing the most up-to-date work. For example, signposting to work posted on the Asia-Pacific League Against Rheumatology (APLAR) website, which offer resources for nurses across Asia-Pacific to download. There are teach-the-teacher style programmes to support them initially, before they may move onto undertake something like the European League Against Rheumatism (EULAR) course. What I'm trying to do is encourage them in every way possible, and these are exciting projects to be part of. Supporting and offering resources to new rheumatology nurses is key to the future of the specialism. I've also just published a second edition of the Oxford University Press Musculoskeletal Handbook. I worked with some excellent contributors to get it out there and I think it is a really good resource.

Q6 Could you tell us what your role entailed whilst you served 4 years as Chair of the EULAR Healthcare Professionals Standing Committee?

It's a big organisation and you're working with many different countries. The role was really about being part of the executive team helping to form the way forward for EULAR and to provide a sense of the type of work carried out and issues facing all healthcare professionals such as nurses, physiotherapists, psychologists, occupational therapists, podiatrists, and doctors. As Chair I was representing the healthcare professionals' experiences, knowledge, and developmental needs with the context of the committee's remit. Members of the Executive Committee identify

key issues that are relevant to improving patient care and help healthcare professionals in all areas to deliver evidence-based practice. The Health Professionals Standing Committee also help to form the scientific programme for EULAR each year. As chair I also focussed on encouraging more countries to join EULAR as country members in the Health Professionals category, a key issue allowing greater representation at the EULAR congress.

Q7 Were there any projects you led whilst serving as Chair that you are particularly proud of?

When you're Chair, you pick up work from the previous Chair and build on what they have done. Equally, when you walk away, it's a very humbling thing because it's as though you were never there, as the work carries on. I'm particularly proud of the fact that previously we had 10 or 12 healthcare professional organisations on the EULAR group as country members, and that's now 25. I spent a lot of time visiting other countries in Europe who wanted to join and mentored them along the route to submitting to the Executive Committee for EULAR membership.

Q8 In 2014 you were recognised in the Queen's birthday honours list and awarded an Order of the British Empire (OBE); do you think this will have raised the profile of rheumatology as a speciality?

For me it was a big surprise and I was incredibly proud. Apparently, to be able to be considered for submission you require significant support from a range of organisations before you can be considered. So, it was a very humbling experience for me because I worked in an unusual way in that I was an independent nurse consultant, working with the NHS, but also undertaking different pieces of work with different organisations. It was an unusual model compared to most other nurses. So, for me, that was a very strong endorsement of what I was doing. I hope, in some small way, it has raised the profile for rheumatology nursing, and for patients.

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