

EULAR Study Group for Collaborative Research

Study Group leader: Dr. Maarten de Wit

During the previous two decades, the interest in patient-centred care, developing patient reported outcomes (PROs) and forms of collaborative research has grown. In the field of rheumatology, many efforts to initiate, develop and implement collaborative research have been undertaken and reported. EULAR PARE has developed recommendations for patient-researcher collaboration and has also established a network of 40 trained patient research partners (PRPs), of whom six have also graduated from the EUPATI training course.

The EULAR Study Group for Collaborative Research enables participants at the EULAR congress to meet once a year, agree on a research agenda and initiate new collaborations.

Aims of the Study Group for Collaborative Research

- To create a platform for knowledge exchange regarding patient participation in rheumatology care and research.
- To disseminate research priorities to the wider community to inform future research studies.
- To establish a community of practice comprising researchers and PRPs with an interest in developing new and innovative methods to make the voice of patients heard in rheumatology research.
- To develop recommendations and criteria to enhance patient-researcher collaboration on international, national and local levels.
- To stimulate the dialogue about the rationale, principles and conditions for patient involvement and collaboration in research.
- To enhance the implementation of recommendations for patient-researcher collaboration, for example, in EULAR grant applications.
- To discuss and develop the nomenclature and methodology of evaluating the process, results and impact of patient participation in research and health care improvement and innovation.
- To develop patient participation in such a way that it advances care and research in rheumatology.

The study group is open to anyone who is interested.

Founding Members

Researchers	Patient Research Partners
<p>Bente Appel Esbensen, Glostrup (DK) Steven Black, Keele Univeristy (UK) Prof. Rinie Geenen, Utrecht University (NL) Prof. Laure Gossec, Université Pierre et Marie Curie (FR) Prof. Sarah Hewlett, University of the West of England (UK) Prof. Ingvild Kjekken, National Advisory Unit on Rehabilitation in Rheumatology (NO) Dr. Heidi Lempp, King's College (UK) Jorit Meester, Leiden University Medical Centre (NL) Prof. Christina Opava, Karolinska Institutet (Sweden) Prof. Karim Raza, Birmingham University (UK)</p>	<p>Nele Caeyers, Belgium Jen Horonjeff, New York Florian Klett, Switzerland Marios Kouloumas, Cyprus Kirsten Lerstrøm, Denmark Souzi Makri, Cyprus Elsa Mateus, Portugal Mascha Oosterbaan, Netherlands Dora Papastavrou, Greece Pam Richards, UK Maria Vella, Malta Marianne Visser, Netherlands Dieter Wiek, Germany Maarten de Wit, Netherlands Codruta Zabalán, Romania Savia de Souza, UK Simon Stone, UK</p>