

EULAR Patient Research Partners Network

PRP's training meeting in Amsterdam, October 2017



Background

Patient involvement in research projects improves the quality of study designs and leads to a more efficient implementation and evaluation of research findings. It increases the credibility of research projects and often to more cost-effective health care services. This all results in better health outcomes for patients as well as a higher quality of life for people with rheumatic and musculoskeletal diseases.

The network of EULAR patient research partner (PRPs) comprises 59 PRPs (January 2018). The network has established itself as a reliable source of trained and dedicated research partners. The number of projects in and outside of EULAR in which PRPs actively participate has expanded dramatically over recent years (Fig. 1). The EULAR Patient Research Partners network is coordinated by the EULAR Secretariat.

EULAR

- Management Recommendations
- Points to consider
- Classification criteria

Health Professions Projects

Review of lay summaries of Annals of the Rheumatic Diseases

EULAR Study Groups

Review of Grant proposals

- Patient reported Outcomes
- Pain
- Osteoarthritis

FOREUM

Research Foundation

- Executive Committee member
- Scientific Committee member
- Involvement in research applications
- Involvement in research projects

Secretariat

- Coordination of the EULAR PRP network
- Implementation of recommendation for inclusion of PRPs in scientific initiatives
- Advising researchers

Optional

- Pharmaceutical industry
- National PARE organisations

EU Research Programs

Horizon 2020

- HarmonicSS
- GLORIA
- APPROACH

Innovative Medicine Initiative

- BTCure/RTCure
- EUPATI
- EUROteam

EMA Consultations

- Rheumatoid Arthritis
- Adult onset Still disease
- Systemic Sclerosis

Fig. 1: PRP involvement in scientific projects

Key Indicators of the EULAR Network of PRPs

- 59 trained PRPs in the network
- More than 95 EULAR projects with PRP involvement since 2008
- 20 PRPs participated in EULAR projects in 2016 – 2017
- More than 110 ARD lay summaries reviewed by PRPs since September 2014
- 18 EULAR Recommendations lay summaries reviewed by PRPs
- 7 certified EUPATI fellows in the EULAR PRP network
- 3 PRPs represented in EMA advisory committees
- 6 EU-funded projects with active EULAR PRP involvement (BTCure, HarmonicSS, IMI patient involvement strategy, APPROACH, EUROTEAM and RTCure)

Reference cards and Brochure



Fig. 2
Cards Patient Involvement



Fig. 3
Brochure reference cards explained

Publication:
European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects.

De Wit MP, Berlo SE, Aanerud GJ, Aletaha D, Bijlsma JW, Croucher L, et al.
Annals of the rheumatic diseases.2011; 70:722-726

EULAR Recommendations: Lay versions

Since 2014, EULAR provides English lay summaries of its disease management recommendations. EULAR calls on all interested organisations to disseminate the lay summaries and encourages the translation into the respective, national language. For

EULAR it is essential that the dissemination of the lay versions of the recommendations reach patient organisations, as well as healthcare professionals, in order to support patients and carers in managing their disease. The lay versions are reviewed by PRPs. View them at: https://www.eular.org/lay_recommendations.cfm