

# EULAR GUIDE: STARTING A PATIENT RESEARCH PARTNER (PRP) GROUP ON A NATIONAL LEVEL

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## Contents

Introduction: Patient involvement in rheumatology research .....	3
Establishing a network is key.....	3
Building a community of practice.....	4
Five steps to starting a national PRP network.....	4
Finding RMD patients willing to become a PRP .....	6
Who could support you in building a national PRP network? .....	7
PRP training.....	7
Costs and funding .....	8
Ensuring a network's continuity and sustainability .....	9
Useful Information .....	9
Further reading.....	11
Contacts .....	12
Template profile of a national PRP facilitator .....	12
Tasks .....	12
Requirements.....	12
Support.....	13

## Introduction: Patient involvement in rheumatology research

Over the last decade, the role of patients in rheumatology research has increased considerably. The European Alliance of Associations for Rheumatology, EULAR, has taken a leading role in promoting this progression by developing recommendations and mandating involvement of Patient Research Partners (PRPs) in all its taskforces and other scientific initiatives. Also, on national and regional levels, there is an appetite to explore different patient roles in research other than that of study participants. For that reason, EULAR has decided to produce this guide to support patient groups to establish and support their own PRP networks.

As defined in the "[EULAR recommendations for the inclusion of patient representatives in scientific projects](#)", patient research partners are "persons with a relevant disease who operate as active research team members on an equal basis with professional researchers, adding the benefit of their experiential knowledge to all phases of the project".

Active collaboration between patients and researchers seems to be an appropriate means by which to capture the patient perspective. Patient participation ensures better representation of their needs and uncertainties and helps prevent a potential mismatch between their preferences and the scientific focus in research. Other potential benefits for researchers are:

- More patient-oriented health research agendas
- Gaining trust and access to patient organisations and other institutions
- Raising funds for research
- Creating support for implementation

Patient involvement may result in the empowerment of people with rheumatic and musculoskeletal diseases (RMDs) and enhance a sense of ownership. Finally, the development of an involved patient community that is better informed – and recognises the value and limitations of research – is also in line with the need and desire, at the regulatory and political levels, to place the patient at the centre of all research processes and strategies.

Only a few European countries have national policies to include patients in research – with the UK as an illustrative example of supporting patient and public involvement (PPI) through a top-down approach. According to National Institute for Health Research (NIHR) policy, no research can be funded unless there is active patient involvement. This decision has supported the rapid implementation of collaborative research principles, and many centres have developed so-called research user groups, supported and promoted by PPI co-ordinators.

In other countries, the principles of collaborative research were developed bottom-up – where individual patients or researchers took the initiative and started from scratch by developing a patient group and providing on-the-job training. In the ideal world, the implementation of partnership would be supported by both strategies: bottom-up as well as top-down.

## Establishing a network is key

The PARE (People with Arthritis/Rheumatism in Europe) PRP Working Group, together with members of the EULAR Study Group for Collaborative Research, collected tips for starting a PRP network on a national level. It is based on the Dutch and German experiences that were reviewed by co-ordinators of patient involvement panels, patient research partners and researchers from many countries across Europe.

PRPs should not work in isolation, and they should benefit from the support of other PRPs. We will use the term "network" to emphasise that a key success factor of establishing an effective PRP group is the opportunity to learn from each other by frequently exchanging experiences. All PRPs benefit from regular

meetings with their peers to stay motivated, to present case studies and to discuss challenges. As a result, PRPs can build their confidence and improve their skills to enable them to collaborate with researchers. Such networks can be established on different levels, as we have seen at the:

- International level, such as GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) PRP network
- European level (EULAR)
- National level (Germany, Netherlands)
- Regional level (Keele, UK; Sonderborg, Denmark)
- Local level

This guide describes the establishment of a PRP network on national level, but we hope these principles and steps can be extrapolated to other levels of health research.

Finally, these networks can comprise PRPs with all kinds of RMDs, but can also be disease specific. The European HIPPOCRATES research consortium, for example, has established a network of PRP who have psoriasis or psoriatic arthritis. The HarmonicSS consortium enabled the establishment of another disease specific (Sjögren's syndrome) PRP network.

### Building a community of practice

We will use the term "community of practice" when we refer to the structured communication between PRPs, researchers, relatives, patient organisations and other stakeholders about the development and implementation of collaborative research projects.

An important example of such a community of practice is the [EULAR study group for collaborative research](#). Similar initiatives can be created on national, regional and local levels. When they function properly, beneficial learning, relationship building, interaction and synergies will emerge between these different communities – a community of communities.

### Five steps to starting a national PRP network

There is no official blueprint for setting up a PRP network. One way could be via the following five steps.

Step 1:

Try to secure the **back-up of a national patient organisation** or **umbrella organisation** for people with RMDs.

The idea of participatory research – and its advantages – needs to be presented to the leadership of the national patient organisation(s). Literature such as the "[EULAR recommendations for the inclusion of patient representatives in scientific projects](#)", and the [EULAR brochure](#) and [reference cards](#) can help you prepare this presentation. The ideal result should be that the leadership recognises the added value of a PRP network and subscribes to its development.

Step 2:

Establishing a successful and sustainable network of PRPs requires resources in terms of money, time commitment and people power.

Set clear **expectations** with your patient organisation as to how much resource (time, funding, people power, etc.) you can apply to establishing a PRP network – and adjust PRP start-up activities according to the amount of resources available. Preferably, find a partner with previous experience of working with PRPs who can advise and/or help start up the PRP network. This can be an already-active patient research partner,

a health professional, physician or nurse, a carer (there are different models that work). It can also be an experienced PRP from a neighbouring country.

If the leadership is convinced, a source for funding must be found. Funding is necessary for setting up the PRP network (See: Costs and funding).

Step 3:

Set up the **infrastructure** for a PRP network.

- Agree on **basic principles** about the role and responsibility of the PRP network by answering questions such as:
  - What is the purpose of the PRP network?  
(PRP involvement in guideline development, research and development, policy making, education of future RMD professionals)
  - What will be the geographical scope of the PRP network?
  - How will the PRP network be established?
  - How will the PRP network be funded?
  - Will you have different types of PRPs or different projects – and what would be the necessary experiences, qualifications and/or skills?
  - How will the PRPs be trained and how will the researchers be trained?
  - How will the PRP network be co-ordinated?
  - How inclusive will the roles and processes be?
  - How can the network grow?
  - How will the impact of the PRP involvement be evaluated?
- Set up a **website or webpage with information** about the PRP network for patients as well as for stakeholders that would be interested in PRP involvement. The page can be hosted by the national patient organisation or it can be an individual website with clear links to the stakeholder organisation.
- Set up an **inspiring PRP vacancy text and general task description** for the (possibly different types of) PRPs you are looking for.
- Develop **(written) information for potential PRPs about expectations regarding their new role/responsibilities**:
  - Introduction of the PRP programme, its impact and how it will be evaluated
  - Information about the PRP training: What will the training include? How much time is required? Who will undertake the training?
  - Compensation and guidance during projects: What will be reimbursed? Who should be approached?
  - Meetings of the PRP network (See: PRP training).
- Set up a **database** for future PRP **administration** that complies with the General Data Protection Regulations (GDPR).
- Set up a **database** for the **monitoring** of future projects.

Step 4:

Agree on a **research agenda** with your patient organisation.

A research agenda is set by people with RMDs and includes the top 10 RMD research topics that people with RMDs identify as deserving the most attention. Building the research agenda in collaboration with other stakeholders can be very beneficial for future collaborations in the field of research – and it can be a great start in establishing a PRP network.

A German case study about developing a national research agenda will be presented in one of the PARE Best Practice webinars in October 2021.

## Step 5:

Publish the research agenda and **share its results with stakeholders** of your patient organisation – board, members, health professionals and researchers, politicians and other decision makers, donors.

This can be via presentations during conferences and events, in publications and online newsletters, and on social media. End each message with a call to action, such as:

- For patients: Join our PRP Network. Share your experience and help make RMD research important and relevant to patients and carers. For more information look at [www...](#) and contact...
- For RMD professionals: Focus on RMD research that matters to patients and carers. Join forces with our PRP Network. For more information look at [www...](#) and contact...

You don't need to start too big. It is often sensible to get going with one project and learn from the experience. This can lead to a new project, which then leads to new invitations for more projects – like a snowball effect. The key is maintaining dialogue with researchers and, at the same time, balancing the number of projects in which you wish to participate – and having enough interested and motivated PRPs to participate in these projects. The overall advice is to start small, be honest and admit when you don't have enough capacity, and gradually grow as more PRPs become available. The next important step is to evaluate the progress of the network, as well as to evaluate the collaboration with researchers in specific projects.

### Possible patient roles

- Recommendation Task Force member
- Patient reviewer (research proposals, national guidelines)
- FOREUM committee member
- Reviewer of lay summaries
- Member of the European Medicines Agency (EMA) committee
- Member of a pharmaceutical company's advisory committee
- Member of an international patient panel for international research ("consortia")
- Patient Research Partner in a PI-initiated study
- Patient Research Partner involved in a specific research study
- Participant in hospital RMD departments' research projects on a national level

*Examples of the types of patient involvement in the EULAR PRP network*

## Finding RMD patients willing to become a PRP

### Recruitment

There are different ways of identifying eligible PRPs. In a way which conforms to GDPR, ask for personal information like age, experience with RMDs and a motivational statement.

- Start with **your own network**: Which people do you know who might be interested in – and capable of – becoming a PRP? Do they know other people who might be interested? Find out if any members have already been involved in research studies as PRPs and if they know other people who are also active.
- Ask **active members of your patient organisation** if they would be interested in becoming a PRP. For example, the patient organisation needs to send out emails to all members describing participatory research and its aims, and asking for interested volunteers.
- Ask the **RMD professionals** (rheumatologists and RMD nurses) that are connected to your patient organisation or local patient/carer groups if they have members who would be interested in – and capable of – becoming a PRP.

- Share the aims and goals of the PRP network during **all events that are organised by your patient organisation**.
- Advertise on your patient organisation's **social media channels**. Existing PRPs can share their experiences in a video or post. Social media outlets are important but not everyone uses them, so it would be ideal to use multiple communication channels to reach your members (your magazine, email, organisation's journal, newsletter etc).
- As a next step, you can consider setting up a blog for the PRP group so that everybody can read what the members are involved in. This helps to raise the profile and can be linked to other organisations (for example: <https://mskexpertpatient.wordpress.com/>).
- Try to recruit a broad and diverse range of patients.

### Who could support you in building a national PRP network?

These are the possible partners that can help in building a national PRP network.

- Active members of your local or national RMD patient organisation
- Other patient organisations with a main focus on RMDs
- RMD hospital departments (academic/regional)
- Researchers within the field of RMDs (preferably those who already have positive experiences in collaborative research)
- National scientific/clinical/professional/allied health professional societies representing rheumatology
- International EULAR PARE Network of PRPs, EULAR Study Group for Collaborative Research, other PARE organisations
- Patient organisations for other long-term diseases, which already have a PRP network or are interested in establishing one.
- National charities, government institutions or companies which could be approached for funding (setting up a database of PRPs, travelling costs etc.) In some countries, it might not be acceptable for a pharmaceutical company to support the setting up of a patient organisation-driven PRP network.

### PRP training

Training is important to give people with RMDs confidence in sharing their lived experiences of RMDs with other stakeholders at the research table.

Possible induction training topics include:

- Basic principles of evidence-based medicine
- What patient participation in research is about
- Educating PRPs about the different stages of research and how they can contribute to each of them
- How to get access to information
- How to speak on behalf of people with RMDs
- Learning how to recognise the moments in which the patient's voice can make a difference in a meeting
- How to interact professionally with stakeholders by expressing a different opinion.

An induction training course and regular refreshment courses are a prerequisite for the successful inclusion of PRPs in research projects, and for setting up a stable network of PRPs. To support PRP networks, EULAR is currently developing an English language online training course that will start in September 2022. It will be available to all people with an interest in collaborating in research. The training course is supposed to enable patients to make valuable contributions to research projects. In addition, the training course aims to lower barriers and strengthen patients' self-confidence in order to facilitate their integration into the unfamiliar environment among researchers. In the longer term, the course – or its most important parts – should be translated into national languages and accompanied by the "train the trainer" course.

Regular knowledge update is important. By coming together 1-3 times a year as a network of PRPs, you can share experiences and challenges in your projects. Together, you can find answers and explore solutions to any problems that you have encountered. Due to the pandemic, we have learned that virtual meetings can provide an opportunity to meet more regularly. It is also a cost-effective way to meet each other if budgets are tight.

In the UK, some PRP groups are linked with universities, and patients/carers are given a “visiting appointment contract”. This allows them to access any courses offered by the university – including research method courses – and to meet other researchers who they can learn from and network with.

For guidance on training, possible topics and help with finding the suitable trainers, please contact the EULAR Office.

### Costs and funding

As said before, establishing a successful and sustainable network of PRPs requires resources in terms of money, time and energy. Don't underestimate the amount of time that is necessary to build a PRP network, to recruit and train volunteers, and to work on developing a friendly environment among researchers.

This requires investing in a dedicated person for up to 20 hours/week for at least one year. Although this can be done on a voluntary basis, or as a shared responsibility between two people, it is more likely that appointing a paid staff officer would avoid overburdening, and ensure that continuity and a professional outreach can be achieved.

#### **Costs to be considered when setting up a PRP network of a minimum of 12 PRPs (one-time costs):**

- A PRP network co-ordinator (12-20 hours/week).
- Creating a website.
- A brochure (in your own language) about the PRP network for future PRPs.
- A brochure about the PRP network for researchers/RMD professionals.
- Setting up a PRP training programme. If this is not possible, the international EULAR PRP training programme could be very useful.
- Materials for the PRP training programme.
- Setting up a PRP database.
- Setting up a programme for monitoring projects.
- A meeting location for PRP network training and meetings.
- Trainer costs.
- Introduction and ongoing communication with PRPs to keep them involved.
- Communication with researchers in the local area to promote collaborative research.

#### **Costs to be considered for maintaining the PRP network (long-term costs):**

- Ongoing co-ordination of the PRP network.
- Hosting the website.
- Compensation for PRPs. Travel expenses and accommodation should always be reimbursed – preferably by the research group, otherwise by the patient organisation. Patient organisations should consider requesting payment for their efforts in recruiting, training and supporting PRPs, and matching them with research projects.
- Remuneration. Discussion within the patient organisation (administrative board, CEO, PRPs) is needed as to whether or not remuneration for the PRPs' work should be introduced. If yes, remuneration of PRPs' work should be considered when talking with researchers.
- Costs for follow-up training.
- Costs for PRP network meetings.
- Costs for the evaluation of PRP involvement.
- Ongoing communication with PRPs to keep them motivated.

- Ongoing communication with healthcare providers and researchers in (future) projects.

These costs **can be financed through:**

- A regular/annual specific budget within the patient organisation that is reserved for patient engagement in projects.
- A specific budget that is reserved for patient participation in the researcher project application. In some European countries, this is essential and mandatory for many funders.
- A specific budget reserved for patient participation in a project that is carried out by your own patient organisation.
- Some countries have funding options (national charities, government institutions) for patient organisations who want to start up networks such as a PRP network.
- Pharmaceutical companies may be interested in the establishment of a PRP network.
- Application to EULAR to obtain one of the EULAR Knowledge Transfer Programme bursaries.

### Ensuring a network's continuity and sustainability

The sustainability of a network depends on several factors.

- Having trained PRPs willing and available to participate for the length of the research projects.
- Receiving invitations to take part in research projects, approaching research teams directly or leading research projects as PRPs with researchers.
- The co-ordination of the network's activities: Finding and supporting PRPs, finding projects, setting out your own projects, matching PRPs to projects, monitoring and evaluating projects, training PRPs and researchers, hosting meetings with the PRP network (ideally managed by a paid employee).
- Having sufficient funding means all the necessary costs can be budgeted for and will cover all activities.
- Regular refresher courses are mandatory for updating skills and strengthening the PRP network.
- Evaluation and impact measurement of PRP involvement is an important factor for sustainability.

### Useful Information

#### EULAR

The European Alliance of Associations for Rheumatology, EULAR, is the organisation which represents people with arthritis/rheumatism, health professionals in rheumatology (HPR) and scientific societies of rheumatology of all the European nations.

#### EULAR Patient Research Partners Network

The EULAR network of competent patient representatives can be contacted whenever a need for active participation of trained patient research partners is required.

#### EULAR Study Group for Collaborative Research

EULAR study groups are established networks in their respective fields and play an active part in the research and treatment of rheumatic and musculoskeletal diseases. The EULAR Study Group for Collaborative Research enables participants to meet virtually twice a year, agree on a research agenda and initiate new collaborations.

#### EULAR recommendations for the inclusion of patient representatives in scientific projects

To provide guidance to task force leaders and patient research partners, EULAR has developed a set of recommendations for the inclusion of patient representatives published in the "Annals of the Rheumatic Diseases".

#### Guiding brochure and reference cards

Following a review of initial experiences with the PRP concept, the EULAR task force in charge of training the patient research partners and setting up the network developed guiding documents (reference cards and an explanatory brochure) that are freely available. These materials have been created with the support and input of a stakeholder group active in the field of rheumatology research. The reference cards and brochure are currently under review and will be updated in autumn 2022.

## Glossaries

- <http://oml.eular.org/glossary.cfm>  
<https://toolbox.eupati.eu/glossary/>
- <https://bestpractice.bmj.com/info/toolkit/ebm-toolbox/a-glossary-of-ebm-terms/>
- <https://www.invo.org.uk/resource-centre/jargon-buster/>
- <https://www.ema.europa.eu/en/about-us/about-website/glossary>
- <https://omeractprnetwork.org/publications>

## Other links:

- [The Pathway of Patient Engagement in Rheumatology Research](#)  
The purpose of the *initial* pathway is to trace the evolution of patient engagement in rheumatology research, including identifying historical milestones, novel “firsts” and tools.
- [National Institute for Health Research UK](#)  
Learning for involvement training website.

## Further reading

Clare Jinks, Pam Carter, Carol Rhodes, Roger Beech, Krysia Dziedzic, Rhian Hughes, Steven Blackburn, and Bie Nio Ong: Sustaining patient and public involvement in research: A case study of a research centre, *Journal of Care Services Management* 7(4) (2013) 146-154.

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## Contacts

For further information please contact: Alzbeta Goehmann at the EULAR Office ([email here](#)).

## Template profile of a national PRP facilitator

This template profile was developed following discussion among members of the EULAR PRP network during the training and evaluation meeting in 2019 and is based on experience of the members of the EULAR Study Group for Collaborative Research.

## Tasks

- Mapping the current situation of collaborative research in your country.
- Collaborating with other RMD communities (networks, organisations etc).
- Building bridges between the worlds of patients, health professionals and researchers.
- Co-ordinating the network, including organising appropriate training for PRPs.
- Making the network representative of all RMDs (applicable for umbrella networks).
- Contacting researchers and research institutions to explore opportunities for collaboration.
- Recruiting and mentoring new PRPs.
- Motivating and supporting PRPs.
- Matching PRPs with researcher requests.
- Participating in the annual EULAR PRP facilitator meeting, sharing best practices and attending the EULAR study group meetings.

## Requirements

- English language.
- Management skills.
- Leadership.
- Honesty, ethical approach, transparent working.
- Commitment to engage with the public, and ability – and confidence – to work and talk with different kinds of stakeholders (public and professional).
- Ability to work with volunteers.
- Communication skills – including empathy and understanding, and the ability to be involved in personal and sensitive discussions.
- Interest in research, wanting to make a difference.
- Basic knowledge of legal requirements (e.g. GDPR and research ethics).
- Time management skills.
- Willingness to follow the EULAR PARE online training course when available.
- Person with lived experience (desirable).
- “Can-do” attitude, flexible but with a sense of “duty of care”.

## Support

- Support and recognition from the national patient organisation.
- Being part of an international network of PRP facilitators from other countries (annual meetings).
- Support of EULAR – particularly important for countries where collaborative research is still not accepted.
- Training and education. Continuous education; online training course.
- Support from other institutions such as the European Patients' Academy on Therapeutic Innovation (EUPATI), EURORDIS Rare Diseases Europe.
- Payment of expenses, financial support by national patient organisation.
- Having a “buddy” (for example a PRP facilitator in another country).
- Having 1 or 2 co-facilitators (nice to have).