Reumatiker förbundet

Handbook for researchers

A GUIDE FOR REWARDING COLLABORATIONS WITH PATIENT RESEARCH PARTNERS

THE SWEDISH RHEUMATISM ASSOCIATION | REUMATIKER.SE/FORSKNING/FORSKNINGSPARTNER
Adapted from EULARs Reference cards (2013) for the involvement of patient research partners in scientific projects; 2023.

Content

Getting started with patient research partners (PRPs)

1. Early is best...

But it's better late than never. Try to include PRPs as early as possible in the process. This gives them the best opportunity to contribute to the project. Are you already at a later stage? PRPs can contribute there too. The most important thing is that you get the collaboration started!

2. Get in touch with a PRP

To get in touch with one of Reumatikerförbundet's PRPs, fill in the form on the association's website. If you choose to recruit locally, contact forskning@reumatiker.se to discuss training for the PRP.

3. Review your budget for the PRPs' remuneration

PRPs should be offered payment for the time they spend on the project, as well as having the costs of travel and accommodation covered. Guidelines for PRPs' remuneration can be found on Reumatikerförbundet's website.

4. Prepare for the collaboration

Reflect on what you want from PRPs within your project and how you can support them in obtaining the necessary knowledge regarding the research area and project. Consider preparing information for them in lay language.

5. Involve PRPs as much as possible

PRPs can contribute to several aspects of the research process. Look through page 6 for inspiration on how PRPs can contribute to your project in particular. Examples include assisting in creating questionnaires, contributing to applications to the ethics committee, and writing lay summaries.

6. Jointly create a plan for the collaboration

Discuss your respective expectations and roles in the collaboration. Determine communication channels and how regularly contact should take place.

7. Review meeting styles

In order for PRPs to contribute in the best possible way, they need to feel safe and know that their opinions are important. Increase their engagement by asking for their opinions regularly, communicating in lay language, and explaining jargon when it comes up. Discuss the best way to meet (face-to-face vs. online) and adapt as required in order to be inclusive.

8. Give and receive feedback

Regularly discuss how the collaboration is going and what can be improved so that PRPs can contribute to the research in a more effective way.

Questions and answers about patient research partners (PRPs)

What is a patient research partner (PRP)?

PRPs are usually people living with a rheumatic or musculoskeletal disease (RMD), but can also be relatives or carers that have seen loved ones living with an RMD. By living with a RMD, they have unique knowledge both about their own disease and what it is like to live with it.

According to researchers and PRPs who have collaborated, a PRP is:

- *Part of the research group.*
- *The link between patients and researchers.*
- *A person that ensures that the patient perspective is at the heart of the research.*
- *A person with lived experience of the condition being researched.*
- *A discussion partner with a different set of perspectives and insights [from the researchers].*
- *An active participant [in the research team] that contributes valuable views and new perspectives.*

EULAR definition

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 any phase of the project.

Why should patient research partners (PRPs) be included in the research?

1. **Contributing different perspectives**

PRPs bring a different and important perspective to the research. Their perspective is gained from living with the condition studied, and is not something that can be gained through research or clinical work. In addition to bringing the patient perspective to the research team, they also contribute a broader societal perspective.

2. Improving the quality and feasibility of research

The inclusion of PRPs in the research group encourages discussions on how the research can be carried out in the best way. They can promote continuous reflection, challenge assumptions, and improve the quality of the research. Involving PRPs can also improve the feasibility of the project as PRPs ensure that what is requested of study participants is realistic and takes into account the person's situation.

3. PRPs make research more relevant

PRPs can give input on what is important to patients and strive to ensure that the research meets their needs. This includes setting the research question and determining what outcomes should be included. In this way, PRPs ensure that the research is relevant to those living with the disease.

4. Democratic principles

Research affects people living with the condition in question and can also affect the general public. Those affected by the research have the right to have a say in it, and can be empowered by influencing research that affects them. In addition, a lot of research is funded by public funds. Involving PRPs is a way for researchers to increase the transparency of their research and increase public accountability.

5. Involvement of PRPs is increasingly a requirement

Research funders, such as Reumatikerförbundet and the Swedish Research Council, are increasingly asking for PRP involvement in research projects. More journals are also requesting PRP roles and contributions to be specified in manuscripts.

Should patient research partners (PRPs) be compensated for their participation?

PRPs should be compensated for the time they spend on meetings with the research group or steering group, preparation for meetings, and research activities. Include PRP compensation and associated costs in your budget when applying for research grants. Note that social security contributions need to be applied. Guidelines for PRP compensation can be found on the Reumatikerförbundet's website (www.reumatiker.se/forskning/forskningspartner).

Some research groups have experienced difficulties in paying the compensation to their PRPs, so discuss this with your finance department early on to determine how you will resolve it locally. Institutions may choose to pay the compensation in different ways.

How can patient research partners (PRPs) contribute to research?

Below are examples of how a PRP can contribute to research. Reflect on the list. What is planned in your project and how can your PRPs contribute? Discuss with your PRPs and jointly create a plan for their contributions going forward.

Phase	Activity	PRP contributions	☑
Planning	Development of research question	Discussion of research needs	☐
		Contribute ideas about what is important and relevant to patients	☐
	Questionnaire development	Choice of questions	☐
		Wording of questions	☐
		User-friendly formatting	☐
		Estimation of time required to complete	☐
	Interview guide development	Choice of questions	☐
		Wording of questions	☐
	Outcome selection	Choice of outcomes, including PROMs	☐
		Discussion about what is relevant to patients and what is feasible	☐
	Project design	Focus on feasibility – how do you get the right balance of collecting data without overloading the patient	☐
		Intervention's content/structure	☐
	Recruitment	Recruitment strategy – where to recruit from, timing, practical aspects	☐
		Design, wording, and content of recruitment material	☐
	Development of materials for study participants - information materials, informed consent	Design, wording, and content of informed consent form, information material, and documents	☐

”Doing”	Focus groups or interviews	• Leading focus groups/interviews together with researchers	☐
	Qualitative data analysis	• Identification of themes based on their perspective as a patient	☐
	Interpretation of results	• Interpretation based on their perspective as a patient • Discussion about which conclusions are most important to patients and should be highlighted	☐ ☐
Dissemination	Lay summaries	• Wording and content	☐
	Feedback text to study participants	• Wording and content	☐
	Dissemination via other media	• Dissemination strategy to patients, healthcare, and the general public • Wording and content	☐ ☐
Other	Applying for research funding	• Feedback on the application • Plans for PRP involvement and contributions • Wording of the lay summary	☐ ☐ ☐
	Application to the ethical review committee	• Feedback on the application • Discussion of ethical aspects to consider	☐ ☐
	Steering group	• Participation in the steering group to ensure patients remain at the heart of the research	☐
	Significance of the research	• Conversations about how life is affected by the disease and what the research means for patients	☐

Preparations for and during collaboration with patient research partners (PRPs)

Preparatory work

Starting a research project requires commitment, time, and energy from everyone involved. Including a PRP in the process usually doesn't add too much more work. An important prerequisite is that everyone in the group is adequately prepared. This will make collaboration easier once everything is up and running.

PRPs should be included **as early as possible** in the research process, so that they have the greatest opportunity to contribute to the research. But even if the project has already started, is still beneficial to include involve PRPs– it is better late than never!

There are different ways to **get in touch** with a PRP. Information is available on Reumatikerförbundet’s website on how to get in touch with a trained PRP. If you choose to recruit locally, Reumatikerförbundet can offer training and support for your PRP, provided they are a member of Reumatikerförbundet. Be clear about the time required up front when you are looking for a PRP so that they can make an informed decision regarding their involvement.

Patients will all have different experiences, and for that reason, you should consider including at least **two PRPs**. Including more than one perspective can be beneficial to the project.

If it is a PRP’s first assignment, keep in mind that their participation will be a **new experience** for them. They need time to adapt to the group, the jargon, the culture, and your way of working. Give PRPs time and space for this learning curve. Over time, it will increase their motivation and help them contribute more effectively.

Make sure you have realistic and manageable **expectations**. In addition to their role as a PRP, they may also be working parttime or fulltime. Since it is not always possible to get time off work to attend meetings, you should discuss this in the beginning. In addition, living with a chronic disease often takes time and energy, so allow enough time for tasks that need to be done from home.

PRPs need clear descriptions of the project's objectives and **what is expected of them**. Feel free to use the Activity List (page 6) to plan their contributions.

Invite PRPs to an **introductory meeting** before inviting them to larger group meetings. Getting to know each other facilitates collaboration, strengthens trust, and enables discussion about each other's expectations.

Review your **budget** and discuss with the finance department how and when the compensation will be paid to you PRP. Costs associated with involving PRPs include compensation for the time they devote to the project as well as travel and accommodation costs for meetings. Guidelines for PRPs' remuneration can be found on Reumatikerförbundet's website.

Appointing a **contact person** or coordinator helps the PRP to better prepare for the first meeting. The contact person should ensure that the PRP receives sufficient background information. Keep in mind that, compared to experienced researchers in the group, the PRP likely needs more time and information to familiarise themselves with the topic and the goals of the project. The contact person should be available throughout the process to answer any questions thatp may arise.

- Involve PRPs as early as possible in the project.
- Involve at least two PRPs and ensure an appropriate budget for their involvement.
- Plan ahead and be clear about how much time PRP involvement will take, as well as when and where meetings will take place.
- Plan an online or face-to-face meeting before the first group meeting.
- Appoint a contact person that can answer the PRPs' questions.
- Provide (in lay terms, if possible):
    - Background information about the objectives and context of the study.
    - A description of the tasks with clear information about the time involved.
    - A list of the other participants in the group and their backgrounds.

During the meeting

Having PRPs in your group requires meetings to be held in a different way. The **language** must be adapted so that everyone around the table can understand each other. Mutual respect and a willingness to listen and learn are essential. Each person's input is valuable and a good dialogue is essential to achieve the best results.

PRPs share their **personal experiences** of illness as well as what they have heard from others. This does not necessarily reflect the experiences of all patients. In some cases, it is not possible to find a PRP with the condition studied, but it is still beneficial to include someone that keeps the focus on the patient and gives opinions from a broader patient perspective.

Build **trust** within the group. Ensure that PRPs feel comfortable whilst sharing their, sometimes emotional, experiences. Reassure them that their experiences are not discussed outside the group. In addition, PRPs may feel unable to contribute constructively to discussions as they are unfamiliar with how research meetings are structured and do not feel safe enough to voice their opinions. This can be avoided by repeatedly giving them the opportunity to ask questions and ensuring they have enough time to share their views.

For face-to-face meetings, offer the PRP a seat in the **centre** of the group. A seat at the end of the table or outside the group can reduce their engagement.

It's easy to overlook a person in **online meetings**. It is therefore even more important to ensure that PRPs have the time and space to express their opinions.

Things to consider for online meetings

In online meetings between researchers and PRPs, there...

- Is less non-verbal contact.
- Are fewer spontaneous social interactions.
- May be more difficulties with language and communication.
- May be barriers to PRPs being seen and heard.

To counteract this...

- Keep your camera on.
- Ensure that everyone is heard and seen during the meeting.
- Regularly ask PRPs for their opinions.
- Have a clear structure for meetings and send out the agenda well in advance.

Discuss the points on the page 12 and ensure that both parties agree on the collaboration plan.

Use what the PRP **contributes**. Use their input in the same way you deal with suggestions from other members of the research team. Ensure you also tell PRPs how their contributions have been used. For example, if you have included a new outcome in the protocol based on the PRP's suggestion – tell them!

Reflect regularly on the nature of the collaboration. Are there things that can be improved? Were both parties' expectations met? See it as a good opportunity to strengthen and improve your collaboration.

- Create an open atmosphere where PRPs feel safe to express themselves.
- Let PRPs introduce themselves at the beginning of the meeting.
- Encourage PRPs to participate in discussions and regularly ask for their views.
- If possible, avoid jargon. If it is used, explain the terms and provide extra information.
- Think about how the PRPs can be informed and supported during the work.
- Be open and vocal about the PRP's contributions.
- Ensure trust is built and maintained.
- Discuss how compensation is paid and ensure it is done regularly.

Discussion points for the first meeting with patient research partners (PRPs)

1 **What is expected of PRPs in the project?**

Review the list of activities on the page 6 and reflect on which ones apply to your project. Discuss with the PRP and jointly make a plan for their contributions.

2 **Do the PRPs require any particular knowledge or experience? What support will they receive to obtain it?**

PRPs trained by Reumatikerförbundet receive basic training on the research process and the role of PRPs. In addition, they have experiences and knowledge from being patients, from society, and from their employment. Consider whether knowledge beyond that is needed and ensure that PRPs receive the necessary information and support.

3 **What is the timeline for PRP involvement?**

4 **What are the rules regarding confidentiality?**

If there are any rules or special considerations for the project, discuss these with PRPs at an early stage.

5 **What is the plan for contact?**

We recommend having regular meetings as it shows PRPs that their opinions are important and allows them to contribute to discussions in a meaningful way. If this is not possible, let your PRPs know what to expect.

6 **Who is the contact person for your PRPs?**

Ensure that your PRPs have the contact details for that person.

7 **Do you need to make any adaptations in order to be inclusive?**

Discuss what adaptations you and your team may need to make in order for your PRP to contribute fully. You may, for example, need to ensure that any meeting rooms you use are wheelchair accessible or avoid booking meetings early in the morning.

8 **How is compensation paid to your PRPs?**

Make sure you have the information required to pay their compensation.

Feedback

Acknowledge PRPs’ contributions. They often lack feedback on how they have contributed and wonder: "Did I do a good job?". PRPs appreciate feedback and may need encouragement. Let them know when they have contributed something valuable, and if not, what is needed. It is a learning process for both parties.

Provide **feedback** on PRP involvement shortly after the meeting. What was good? What could be improved?

If areas PRPs have highlighted as important to patients do not fit into your project, consider developing a research agenda or list. Future research questions could be guided by what patients perceive as important.

Email contact is good, but **personal contact**, online or face-to-face, is often appreciated.

PRPs are usually not medically trained which can make them feel insecure in a professional setting. Constructive feedback strengthens their **confidence** for future projects.

If PRPs meet the International Committee of Medical Journal Editors' (ICMJE) criteria for **co-authorship,** this should be offered.

Discuss your plans for future **applications of follow-up studies**.

- Provide feedback on PRPs’ contributions.
- Invite PRPs to be become co-authors if they meet the criteria of the International Committee of Medical Journal Editors.
- Discuss possible lessons for everyone in the group.
- Involve PRPs in the development of applications of follow-up studies.