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## CLINICAL SCIENCE

# Patient research partner involvement in rheumatology research: a systematic literature review informing the 2023 updated EULAR recommendations for the involvement of patient research partners

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**ABSTRACT**

**Background** Patient research partners (PRPs) are people with a disease who collaborate in a research team as partners. The aim of this systematic literature review (SLR) was to assess barriers and facilitators to PRP involvement in rheumatology research.

**Methods** The SLR was conducted in PubMed/Medline for articles on PRP involvement in rheumatology research, published between 2017 and 2023; websites were also searched in rheumatology and other specialties. Data were extracted regarding the definition of PRPs, their role and added value, as well as barriers and facilitators to PRP involvement. The quality of the articles was assessed. Quantitative data were analysed descriptively, and principles of thematic content analysis was applied to qualitative data.

**Results** Of 1016 publications, 53 articles were included; the majority of these studies were qualitative studies (26%), opinion articles (21%), meeting reports (17%) and mixed-methods studies (11%). Roles of PRPs ranged from research partners to patient advocates, advisors and patient reviewers. PRPs were reported/advised to be involved early in the project (32% of articles) and in all research phases (30%), from the conception stage to the implementation of research findings. The main barriers were challenges in communication and support for both PRPs and researchers. Facilitators of PRP involvement included more than one PRP per project, training of PRPs and researchers, a supportive environment for PRPs (including adequate communication, acknowledgement and compensation of PRPs) and the presence of a PRP coordinator.

**Conclusion** This SLR identified barriers and facilitators to PRP involvement, and was key to updating the European Alliance of Associations for Rheumatology recommendations for PRP–researcher collaboration based on scientific evidence.

**INTRODUCTION**

Patient research partners (PRPs) are described as individuals living with a health condition who ‘provide input to research, through active collaboration as equal partners with researchers’.<sup>1</sup> Their involvement is essential to make research more patient centred, for instance, by capturing outcomes

**WHAT IS ALREADY KNOWN ON THIS TOPIC**

- ⇒ Patient research partners (PRPs) are increasingly integrated into medical research, particularly in rheumatology.
- ⇒ Major global health organisations recognise the central role of PRPs’ involvement in research.
- ⇒ Previous recommendations have guided researchers and PRPs to build collaborative relations but lack a strong evidence base.

**WHAT THIS STUDY ADDS**

- ⇒ This systematic literature review provides for the first time a comprehensive overview of the emerging role of PRPs in rheumatology research, emphasising their expanding roles, contributions and the value they bring to the research process.
- ⇒ The review identified key barriers to PRP involvement, ranging from personal factors to challenges in training, communication and collaboration, and also identified strategies to enhance PRP involvement.
- ⇒ Early and sustained involvement of PRPs, as well as a supportive environment and effective communication, were found to be essential to enhance the relevance and impact of PRP contribution to research.

**HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY**

- ⇒ Recognising and addressing the barriers to PRP involvement can lead to better support for PRPs, enhancing their involvement in research.
- ⇒ Some facilitators identified include involvement of PRPs since the early stages of research, a supportive environment for PRPs and encouraging researchers to adopt more flexible strategies and behaviours to maximise the benefit of PRP involvement.
- ⇒ This literature review informed European Alliance of Associations for Rheumatology recommendations, highlighting the importance of active collaboration, training, mutual respect, and transparent communication between PRPs and researchers.

that matter to patients. Over the past two decades, the magnitude of PRP involvement and their roles in research has grown substantially.<sup>2–8</sup> Patients have transitioned from passive subjects to active collaborators and equal partners, bringing their unique perspectives and valuable insights to the forefront of medical research.<sup>5</sup> This change has not only profoundly modified research practices but has also underscored the integral role PRPs play in shaping the future of medical practice.<sup>9</sup> The importance of PRP involvement in research has become widely recognised as an essential component of high-quality patient care, highlighted by organisations such as the WHO<sup>4</sup> and European Medicine Agency (EMA),<sup>10</sup> and is acknowledged across various medical specialties.<sup>11–13</sup>

In rheumatology, this paradigm shift has been significant. In 2011, the European Alliance of Associations for Rheumatology (EULAR) developed recommendations for the involvement of patient representatives in scientific projects based on expert opinion.<sup>14</sup> These recommendations marked a pivotal step, setting the stage for the involvement of PRPs in research projects. Since then, these EULAR recommendations have guided other organisations such as Outcome Measures in Rheumatology (OMERACT), Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and the Foundation for Research in Rheumatology (FOREUM), to recognise the important role of PRPs or to develop their own guidelines for collaborative research.<sup>15–18</sup>

As the landscape of patient involvement in research evolves, the literature has witnessed a great surge in data and studies concerning PRP involvement.<sup>2 4 5 15 19–25</sup> These studies not only shed light on the benefits of PRP participation but also highlighted the challenges encountered in this collaborative effort and solutions proposed to overcome barriers.<sup>21 22 25–29</sup>

In 2022, EULAR decided to update the 2011 recommendations for PRP involvement in research, focusing specifically on PRPs in the context of chronic conditions.<sup>14</sup> In accordance with the EULAR standardised operational procedures (SOPs) supporting this update, we conducted a systematic literature review (SLR) to inform the EULAR taskforce.

## METHODS

To support the update of the EULAR recommendations, we conducted in 2023 an SLR that encompassed both qualitative and semiquantitative analyses of recent publications in rheumatology, with the goal of identifying factors that affect PRP involvement, including barriers and facilitators.

### Literature search

The SLR aimed to identify publications reporting PRP involvement in rheumatology research published between 1 January 2017 and 1 January 2023. We searched the electronic database PubMed MEDLINE using the terms “patient research partner”, “patient expert”, “patient and public involvement (PPI)”, their synonyms and related concepts. Details of the search terms and search strategy can be found in online supplemental table 1. Two authors (KA, LG) independently assessed the title, abstract and keywords of every publication identified. In the event of disagreement between the reviewers, disparities were discussed and resolved. Additionally, we performed a scoping review of databases to assess PRP involvement and explored six websites from rheumatology: OMERACT, GRAPPA, American College of Rheumatology, EULAR, FOREUM and Osteoarthritis Research Society International. We also searched 2 regulator websites: Food and Drug Administration and EMA, and 10 websites of

three selected specialties recognised for significant PRP involvement: cardiology, oncology, endocrinology (diabetes) (online supplemental table 2). A specific search was done in two websites focusing on patient and public involvement: INVOLVE UK by the National Institute for Health Research and Education that empowers (European Patients’ Academy on Therapeutic Innovation), and in orphan diseases to answer specific research questions about training, involvement in grant applications and remuneration of PRPs (online supplemental table 3).

The scope of the literature search was defined by the EULAR taskforce steering group,<sup>1</sup> and addressed 11 specific research questions (Box 1).

### Inclusion and exclusion criteria

We included all types of articles reporting PRP involvement in all types of research, including trials and observational studies, qualitative studies, mixed-methods studies and reports of meetings, opinion papers and reviews. We did not exclude published articles from any country, aiming to enhance the generalisability of our findings. Recommendations and guidelines on PRPs were also analysed and were used as supportive information. Articles not focused on rheumatology research or not bringing any information on PRPs (ie, not answering one or more research questions), as well as not in English, were excluded. Articles only mentioning PRPs or their involvement, without providing any details (eg, on their roles, contributions or barriers/facilitators), were excluded as well. Articles with duplicate information (ie, multiple publications reporting on a single study) were excluded if they did not provide additional information relevant to our research questions.

We also identified relevant articles by hand search of the references cited in the included studies, extending the inclusion period to the date of publication of the previous recommendations (2011–2023).

### Data extraction

Data collection encompassed both quantitative and qualitative data, addressing various aspects of PRP involvement and providing answers to our research questions (Box 1). Data were extracted and checked independently by two authors (KA and MdW). Discrepancies were resolved by discussion among the core team (KA, MdW, PS, LG).

### Quality assessment

Papers were assessed for quality only if they reported original data. Review papers, recommendation papers, opinion papers, case studies, study protocols, report papers and qualitative studies not primarily focused on PRPs were excluded from quality assessment. Given the diversity of study types, we used the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies, literature reviews and cross-sectional studies as described in the EULAR SOI.<sup>30 31</sup> This tool, originally developed for qualitative studies, assesses elements such as the clarity of research aims, appropriateness of methodology, suitability of the research design, adequacy of data collection and clarity in reporting outcomes. For mixed-methods studies, we used the Mixed Methods Appraisal Tool (MMAT, a critical appraisal tool that is designed for the appraisal stage of systematic mixed-studies reviews, that is, reviews that include qualitative, quantitative and mixed-methods studies<sup>32</sup> (see online supplemental tables 4 and 5 for quality assessment). To facilitate interpretation, an overall quality assessment for the level of evidence (LoE) was conducted by evaluating the number of items on the

## Box 1 Research topics included in the systematic literature review

1. Definition of patient research partners (PRPs)  
⇒ *How to define a PRP? Is the current definition of PRPs still adequate?*
2. Roles and activities undertaken by PRPs  
⇒ *What are the roles and activities of PRPs in rheumatic musculoskeletal disease research?*
3. Benefits and added value of PRP involvement for PRPs themselves, researchers, the research itself  
⇒ *What is the added value of PRPs in different types of research and groups?*
4. Types of scientific projects that involved PRPs and the stages of the projects in which they participated  
⇒ *What types of projects are (or should) PRPs (be) involved in?*  
⇒ *What phases of a project are (or should) PRPs (be) involved in?*
5. Selection and recruitment processes for PRPs  
⇒ *How are (or should) PRPs (be) recruited and selected?*  
⇒ *How many PRPs are (or should be) involved in the research?*
6. Insights into the experiences and feedback provided by PRPs  
⇒ *What are the PRP feedback and experiences, in terms of facilitators and barriers to PRP involvement?*  
⇒ *How can we improve the PRP experience and involvement overall?*
7. Roles of a coordinator for PRPs in research  
⇒ *Are PRP facilitators involved, if so how, and is it useful?*  
⇒ *Is a facilitator/PRP coordinator recommended?*  
⇒ *What is the reported usefulness of a facilitator?*
8. Training provided to PRPs or researchers  
⇒ *Do the PRPs involved have a specific training (previously/ during the study)?*  
⇒ *How should researchers be educated, trained, supported to enhance PRP involvement?*
9. Evaluation and monitoring related to PRP involvement  
⇒ *How should PRP involvement be monitored or evaluated? At which time points and by whom?*  
⇒ *How should PRP involvement evaluation/monitoring be reported?*
10. Recognition, compensation and acknowledgement of PRPs during their involvement in a scientific project  
⇒ *How should PRP involvement be recognised and acknowledged?*  
⇒ *Is (should) compensation (be) proposed?*
11. Barriers encountered and proposed solutions to enhance PRP involvement  
⇒ *What are the barriers encountered during PRP involvement?*  
⇒ *Which strategies and contextual factors enable optimal engagement of PRPs?*

score checklist and on the key items. Subsequently, the authors reached a consensus on classification of the articles' quality as high, medium or low quality.

This SLR was not considered appropriate by PROSPERO for registration due to the mixed-methods study analyses involved.

### Patient and public involvement

This SLR study is the result of a co-production of three PRPs (MdW, CZ, HB) and five researchers, all being members of the EULAR steering committee responsible for updating the EULAR

recommendations on PRP involvement.<sup>1</sup> The three PRPs actively contributed to all meetings and discussions within the steering committee. They were involved at the early stage of formulating the research questions until reviewing and agreeing on the final manuscript. They were also actively engaged in planning dissemination and implementation of the study findings within the wider community and patient associations. The recruitment of the PRPs was coordinated by one of the PRPs (MdW), the convenor of the project.

### Analysis

For quantitative data, a descriptive analysis of findings is reported, including characteristics of studies (study design, population, country, study objectives), characteristics of PRPs, selection process of PRPs, type of involvement, phases of the research where their involvement occurred, with numbers and percentages using frequency tables and charts.

The number of PRPs involved in the studies was quantified using two distinct methods: first, coauthorship count: direct examination of the research articles' authorship lists. PRPs were identified based on explicit mentioning of their role as 'PRP' or other specific identification. Second, participation count: this approach assessed the number of broader involvements of PRPs in activities of the research project. For instance, in a GRAPPA meeting report, the number of PRPs who actively participated was counted.<sup>8</sup>

Qualitative data were analysed according to the principles of thematic content analysis (more details in online supplemental table 6).<sup>33</sup> The results were discussed within the EULAR task-force,<sup>1</sup> and any disagreements on the interpretation of the findings were resolved by a consensus of the core group (MdW, LG, PS, KA).

## RESULTS

### Search strategy

The SLR yielded a total of 1016 records of which 941 (92.6%) were excluded based on titles and abstracts. We conducted a full-text screening of 75 papers and 46 (61.3%) were included. The main reasons for exclusion were papers not related to rheumatology, lacking reports of PRP involvement in research, being irrelevant to our research questions, or being duplicates or conference abstracts (figure 1). Additionally, 7 papers were identified by hand search, resulting in a total number of 53 included articles.

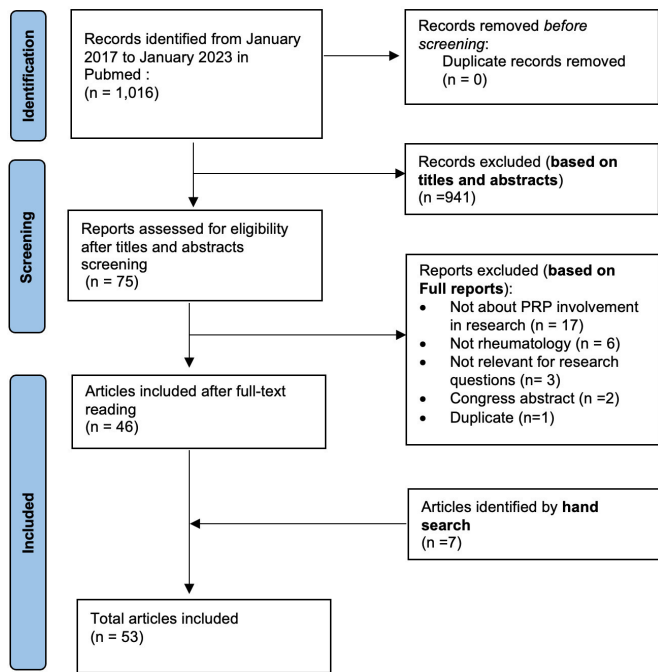
### Quality assessment (LoE) of the papers

Nineteen articles were assessed for quality using the predefined scores according to the study type. Overall, 79% (15 of 19) were classified as high quality, 11% (2 of 19) as medium quality and 11% as low quality (online supplemental table 4).

### Study characteristics

The included studies were qualitative studies (14 of 53, 26%), opinion articles (11 of 53, 21%), meeting reports (9 of 53, 17%), mixed-methods studies (6 of 53, 11%), recommendation articles (4 of 53, 8%), reviews (SLR or scoping review; 3 of 53, 6%), cross-sectional (2 of 53, 4%), case studies (2 of 53, 4%), observational (1 of 53, 2%) and study protocol (1 of 53, 2%) (online supplemental tables 4 and 5).

Overall, 62% were published in rheumatology journals. Geographically, most of the studies were from Europe (50%), followed by North America (31%).



**Figure 1** Flow chart of selected article search on PRP involvement in rheumatology research. PRP, patient research partner.

**Identification of barriers encountered and proposed solutions to enhance PRP involvement**

Barriers to PRP involvement (table 1 and online supplemental table 7) included emotional and personal factors, communication and relationship challenges, inadequate training and

support, difficulties in the research process and pace, as well as collaboration and engagement issues.<sup>2-4 21 22 24-27 34-42</sup> Effective strategies to enhance PRP involvement (table 1) included early involvement, a supportive environment, effective communication and trust, and providing support and training for PRPs and researchers.<sup>7 21 22 26 29 38 40 43 44</sup>

**Definitions of PRP**

Among the 53 included papers, 62% provided a definition of PRP. Importantly, a significant portion (30%) of these papers<sup>4 6 15 26 27 34-36 45 46</sup> adopted the 2011 EULAR definition of PRP as ‘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’.<sup>14</sup> These papers consistently emphasised the importance of active involvement and fostering equal partnerships between PRP and researchers.

Additionally, seven papers (13%) expanded upon this definition by incorporating informal caregivers into the PRP definition,<sup>20 28 37 38 47-49</sup> known as persons, usually family members, who provide unpaid care to someone with whom they share a personal relationship.

**The roles and activities of PRPs**

The roles and activities of PRPs covered a wide spectrum, extending from research partners to patient advocates, advisory roles and participation as patient reviewers (as detailed in table 2 and online supplemental table 8). Their contributions encompassed a diverse range of activities, including providing input in guideline development, shaping research agendas, and actively advocating in scientific and clinical committees.

**Table 1** Barriers and strategies to enhance PRP involvement in rheumatology research

Concept	Barriers	Strategies to enhance patient involvement
Emotional and personal factors	<ul style="list-style-type: none"> <li>▶ Emotional burden</li> <li>▶ Fatigue</li> <li>▶ Need to accommodate PRP needs (physical and knowledge, level of involvement)</li> <li>▶ Lack of trust</li> <li>▶ Time and budget constraints</li> </ul>	<ul style="list-style-type: none"> <li>▶ Provide a supportive environment</li> <li>▶ Provide flexibility and accessible accommodation</li> <li>▶ Allocate adequate resources</li> <li>▶ Practice active listening</li> <li>▶ Recognise PRP contributions</li> </ul>
Communication and relationship	<ul style="list-style-type: none"> <li>▶ Feeling unheard</li> <li>▶ Power imbalance</li> <li>▶ Inconsistent and poor communication</li> <li>▶ Loss of confidentiality</li> <li>▶ Use of medical jargon</li> </ul>	<ul style="list-style-type: none"> <li>▶ Appoint a coordinator to facilitate PRP involvement</li> <li>▶ Clarify patient roles and objectives</li> <li>▶ Exchange mutual expectations early at project initiation</li> <li>▶ Avoid complex medical terminology</li> <li>▶ Ensure open and transparent communication</li> <li>▶ Ensure feedback and trust</li> </ul>
Training and support	<ul style="list-style-type: none"> <li>▶ Lack of awareness about PRP involvement among researchers</li> <li>▶ Overburdening of PRPs</li> <li>▶ Inadequate training and support of PRP</li> <li>▶ Lack of resources and compensation of PRP</li> </ul>	<ul style="list-style-type: none"> <li>▶ Increase awareness about importance of PRP involvement</li> <li>▶ Allocate resources for patient engagement</li> <li>▶ Provide proper training tailored to PRP needs</li> <li>▶ Provide training and support to researchers</li> <li>▶ Appropriate recognition of PRP</li> <li>▶ Encourage PRPs to ask questions and express needs</li> <li>▶ Communicate workloads</li> </ul>
Research process and pace	<ul style="list-style-type: none"> <li>▶ Challenges to recruit PRPs</li> <li>▶ Time commitment for researchers</li> <li>▶ Anxiety about delays in projects</li> <li>▶ Higher demands on resources</li> <li>▶ Forced changes in working practice</li> </ul>	<ul style="list-style-type: none"> <li>▶ Address recruitment challenges</li> <li>▶ Establish realistic timelines</li> <li>▶ Manage researcher and PRP time commitments</li> <li>▶ Build trust through open communication and demonstrate commitment to research progress</li> </ul>
Collaboration and engagement	<ul style="list-style-type: none"> <li>▶ Lack of PRP diversity and representativeness challenges</li> <li>▶ Discrepancies in views</li> <li>▶ Uncertainty in incorporating patient experiences</li> <li>▶ Risk of sharing data prior to peer review</li> </ul>	<ul style="list-style-type: none"> <li>▶ Discuss representativeness and diversity of PRPs within research team</li> <li>▶ Involve PRPs from project inception and clearly define their roles upfront</li> <li>▶ Discuss and address discrepancies</li> <li>▶ Co-create PRP contracts to ensure confidentiality</li> </ul>

PRP, patient research partner.



**Table 2** Activities and roles of PRPs

Areas of involvement	Activities and roles of PRPs
Development/design	<ul style="list-style-type: none"> <li>▶ Guidelines development,<sup>22</sup> including voting on draft recommendations<sup>24</sup></li> <li>▶ PRO development<sup>5,21</sup></li> <li>▶ Grant application<sup>3</sup></li> <li>▶ Survey/questionnaire development<sup>2,3</sup></li> <li>▶ Interview guide<sup>66</sup></li> <li>▶ Tools (educational or others)<sup>3,4,57</sup></li> <li>▶ Patient-facing materials (develop patient information sheets, pamphlets, glossary, distribution and use of booklet, website, poster)<sup>3,6,42</sup></li> <li>▶ Developing or reviewing (recommendations) lay summaries<sup>4,5</sup></li> </ul>
Leadership	<ul style="list-style-type: none"> <li>▶ Establishing a patient association<sup>5</sup></li> </ul>
Co-leadership role	<ul style="list-style-type: none"> <li>▶ Member of steering committee<sup>7</sup> (eg, EULAR, FOREUM, GRAPPA<sup>61</sup>)</li> <li>▶ Member of working groups (eg, GRAPPA<sup>8</sup>)</li> </ul>
Coauthorship	<ul style="list-style-type: none"> <li>▶ Writing research papers (coauthoring)<sup>3</sup></li> <li>▶ Writing research protocol<sup>56</sup></li> </ul>
Education	<ul style="list-style-type: none"> <li>▶ Trainer at a training programme<sup>6</sup></li> <li>▶ Mentoring less-experienced PRPs<sup>38</sup></li> </ul>
Planning	<ul style="list-style-type: none"> <li>▶ Strategic planning<sup>42,47</sup></li> <li>▶ Event planning: organise, communicate<sup>52</sup></li> <li>▶ Interview schedules<sup>3</sup></li> </ul>
Facilitation	<ul style="list-style-type: none"> <li>▶ Session at a conference<sup>53</sup></li> <li>▶ Held sessions in a meeting<sup>68</sup></li> </ul>
Reviewer	<ul style="list-style-type: none"> <li>▶ Grant application<sup>2</sup></li> <li>▶ Research projects (ongoing)<sup>5,58</sup></li> <li>▶ Summaries of scientific publications<sup>5</sup></li> </ul>
Recruitment	<ul style="list-style-type: none"> <li>▶ Support recruitment of PRPs (to a project or association)<sup>3,6,67</sup></li> </ul>
Evaluation	<ul style="list-style-type: none"> <li>▶ Training programme<sup>6</sup></li> </ul>
Participation	<ul style="list-style-type: none"> <li>▶ In dissemination of research results<sup>3,7</sup></li> <li>▶ Attendance of conferences and scientific meetings<sup>3,40</sup></li> <li>▶ In meetings<sup>2</sup>, discussions<sup>66</sup></li> <li>▶ In quality of care improvement programmes<sup>51,60</sup></li> </ul>
EULAR, European Alliance of Associations for Rheumatology; FOREUM, Foundation for Research in Rheumatology; GRAPPA, Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; PRO, patient-reported outcome; PRPs, patient research partners.	

### The added value of PRP involvement

The literature reported that PRPs added significant value across various aspects of research (table 3). Specifically, 53% of the articles indicated that PRP involvement brought benefits for the PRP themselves, that is, better understanding of their medical condition, acquisition of practical skills, improved comprehension of the research process and increased self-confidence.<sup>2,21,25,36,39</sup> Furthermore, 26% of the articles highlighted advantages for the research process, that is, heightened relevance of the research, enhancement of its overall impact and enrichment of the results by adding experiential knowledge.<sup>2,7,21,25,29,36,38,39,45</sup> The positive impact on researchers, reported in 15% of the articles, encompassed deeper insights into research priorities, increased motivation, innovative ideas, awareness of the impact of their work, a comprehensive approach to addressing patients' needs and improved communication in lay language (table 3).<sup>2,21,25,34,36,38,40</sup> The added value of PRP involvement was also reported as advantageous for the wider community by enhancing the acceptance of research that prioritises community benefits.<sup>2,21,25,36</sup>

### Types of research that involved PRPs

PRPs were actively involved in a wide range of scientific projects, including basic, translational and clinical research.<sup>50</sup> Although

**Table 3** Articles reporting on added value of PRP involvement in research for PRPs, for researchers and for the research

Added value for:		Percentage of articles	Number of articles (N=53)
PRPs	Better knowledge of disease	30	8
	Better knowledge of research	19	5
	Acquisition of practical skills	15	4
	Confidence	15	4
	All	Total: 51	27
Researchers	Better understanding of research priorities and needs	19	7
	Increased motivation and focus	9	3
	Gain of novel perspectives and ideas	9	3
	Real-life implication of their work	9	4
	Attaining a more holistic view of patients with RMD	9	3
	Better use of lay language	6	2
	All	Total: 15	8
Research	Enhancement of the relevance of research	50	7
	Improve the impact of the research	21	3
	Bring experiential knowledge to research	21	3
	All	Total: 26	14

PRP, patient research partner; RMD, rheumatic musculoskeletal disease.

the benefits of PRP involvement were less apparent in basic and translational research, some researchers and PRPs recognised the substantial advantages of collaborative partnerships in this area.<sup>3,25,34</sup> A scoping review highlighted the benefits of PRP engagement in preclinical research, including enhanced understanding of basic science research for PRPs, broadened perspectives for researchers, and positive influence on study questions and methods, along with fostering mutual learning, new collaborations, and improved research quality and efficiency.<sup>40</sup> One study reported that researchers were committed to finding more meaningful ways to integrate PRPs into basic scientific research and dissemination of the project results.<sup>3</sup> Strategies to enhance PRP involvement (ie, training, support, PRP-focused tasks) were also reported.<sup>3</sup>

### Research phases in which PRP participated

Early involvement of PRPs in the research was reported or recommended in 32% of the included articles, emphasising engaging PRPs from the inception of a research project.<sup>2,19–22,27–29,34,36–38,43,45,47,51</sup> This early engagement was reported to enable PRPs to actively shape research questions and methodologies in line with their priorities. Additionally, 30% of the articles stressed the importance of PRPs' continuous participation throughout all research stages (table 4).<sup>4,15,21,22,26,35,43,52–54</sup>

### Number of PRPs

The number of PRPs involved in research is shown in online supplemental figure 1. When considering the coauthorship lists, the majority of articles clearly specified the name and identity of PRPs; subsequently, the number of PRPs involved in the writing and reviewing of the article could be easily deduced. Yet, in 19% of cases, the identification of a coauthor as a PRP was unclear. In cases where PRP involvement was explicitly highlighted by coauthorship, 34% of the articles included one or two PRPs per project, 17% of articles included three or four PRPs, and 25% of articles involved more than five PRPs. Notably, single-centre

**Table 4** Articles reporting or recommending PRP involvement in different phases of the research project

Phases of the research project	Number of articles (n) reporting or recommending PRP involvement n (%) (n total=53)
Conception of the study and research question	9 (47)
Study design and planning	9 (47)
Patient inclusion in the study	9 (47)
Data collection	8 (45)
Data analysis	8 (45)
Data interpretation	11 (51)
Dissemination	15 (58)
Implementation	4 (38)
Evaluation	3 (6)
All phases	16 (32)

PRP, patient research partner.

studies commonly involved one or two PRPs as coauthors. One study, which engaged four PRPs, found this number to be beneficial due to the diverse perspectives they brought.<sup>45</sup> Larger-scale international consortia projects recruited a higher number of PRPs, with around six PRPs being identified as an effective group size for facilitating participation and decision-making.<sup>2</sup>

On the other hand, when reporting all PRP involvement and activities in a research project, 36% of the articles reported a number of PRP higher than nine (online supplemental figure 1). Therefore, the number of PRPs involved in research can be higher than the number of PRPs mentioned as coauthors.

### Selection and recruitment processes for PRPs

The selection process of PRPs was reported in 34% of articles (figure 2). PRP selection criteria were mainly language proficiency (11%), research knowledge (6%), disease diagnosis (9%), communication skills and constructive assertiveness (9%), motivation (8%), educational background (6%), experiential knowledge and expertise (6%) as well as travel capability (4%).<sup>2 3 15 19 21 23 24 27 34 35 55-58</sup> Recruitment methods for PRPs were diverse, relying on patient organisations, marketing companies, rheumatology associations, social media, community outreach, clinic visits, personal connections with patients or researchers, word-of-mouth referrals and volunteering.<sup>2 21 34 38 41 44 53 59</sup> Furthermore, 28% of studies emphasised the importance of clarifying patient roles through clear goal-setting and exchanging mutual expectations early in the project

initiation phase.<sup>15 19-21 27 29 36 42 45 47</sup> Additionally, 28% of studies highlighted the need for inclusivity and diverse representation in PRP recruitment.<sup>2 4 15 35 41 42 52</sup>

### Creating a supportive environment for PRPs

A supportive environment for PRPs was reported to depend on several key principles (table 1)<sup>4 19 20 25 36 42 52 53 60</sup>: ensuring a balanced and manageable workload that respects PRP abilities, providing adequate resources and time for PRP involvement, offering support to overcome language barriers, promoting flexibility and offering accessible accommodation to participate in meetings and scientific conferences.<sup>7 21 38 40 43 44</sup> Equal relationships and co-leadership between PRPs and researchers were cited in several papers as crucial, emphasising mutual respect, trust, and open, transparent communication.<sup>7 15 19</sup> Building strong team communication, and establishing informal personal relationships between PRPs and researchers were also found to be important factors to enhance collaboration.<sup>20 38 47</sup> Regular feedback and discussions about the quality of collaboration, combined with ongoing adjustments to meet the needs and preferences of PRPs, were proposed in two papers.<sup>34 45</sup>

### Roles of a PRP coordinator

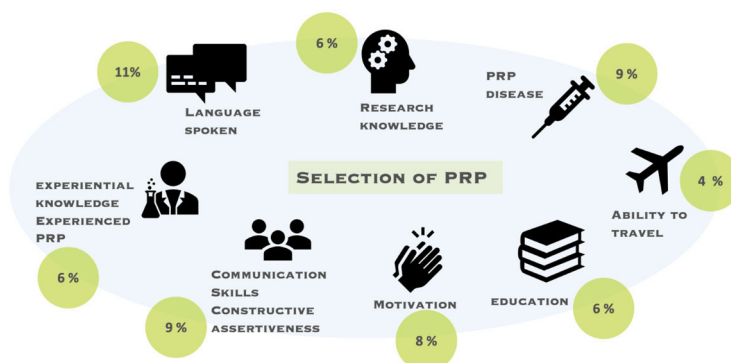
A PRP ‘coordinator’ was defined in some papers, as an individual or a role within a research team responsible for facilitating and supporting the collaboration between researchers and PRPs.<sup>2 20 25 47 61</sup> The presence of a PRP coordinator was reported or advised in 29% of the included articles.<sup>2 3 19 28 34 35 40 42 44 48 61</sup> PRP coordinators were reported to be helpful in facilitating effective communication among PRPs, researchers and stakeholders, aligning expectations, organising logistics, moderating group discussions, providing ongoing education and support, and assisting in the recruitment and selection of PRPs in projects (table 5).<sup>2 20 25 35 36 42 47</sup> This role was reported to be taken by a member of the research team, a PRP or a designated person within a patient organisation or academic institution.<sup>2 38</sup>

### Training of researchers

We found that 34% of the included articles included in the SLR reported or advised training or education of researchers.<sup>4 7 19 21 25 28 29 38-40 44</sup> Researchers could receive training concerning various aspects of working with PRPs (table 6).

### Training of PRPs

Educating and training PRPs was proposed in many papers to enhance the quality of their collaboration with researchers. Notably, nearly half of the publications emphasised the

**Figure 2** The selection criteria of PRPs reported in the studies. PRP, patient research partner.

**Table 5** Potential roles of a PRP coordinator

Competencies	Roles of PRP coordinator
Communication	<ul style="list-style-type: none"> <li>▶ Enable effective communication among patients, researchers and other stakeholders while maintaining neutrality</li> <li>▶ Clarify diverse perspectives, strengths and weaknesses</li> <li>▶ Ensure equal and impartial participation</li> <li>▶ Foster positive social relations between PRPs and researchers</li> <li>▶ Monitor and evaluate PRP strategies</li> </ul>
Project coordination and expectation alignment	<ul style="list-style-type: none"> <li>▶ Mediate discussions to align expectations across all parties</li> <li>▶ Ensure clarity on roles and expectations</li> <li>▶ Organise logistics around PRP involvement</li> <li>▶ Assist at any stage of the research regarding PRP involvement</li> </ul>
Facilitate research discussions	<ul style="list-style-type: none"> <li>▶ Moderate (small) group discussions effectively</li> <li>▶ Encourage deeper discussions through probing questions</li> </ul>
Continuity and education	<ul style="list-style-type: none"> <li>▶ Provide on-demand patient engagement education</li> <li>▶ Maintain training and support continuity for PRPs and researchers</li> </ul>
Selection of PRP	<ul style="list-style-type: none"> <li>▶ Select and invite PRPs for project participation</li> <li>▶ Assist in PRP group development</li> </ul>
PRP, patient research partner.	

importance of training, with 21% recommending it and 25% providing it.<sup>25 28 29 35 37 45 51 62-64</sup> PRP training and support included various aspects (table 6). Training of PRPs was reported to foster well-prepared and empowered PRPs ready to engage effectively in research collaborations.<sup>22 26 29</sup>

### Evaluation and monitoring related to PRP involvement

Around 21% of the included publications recommended or reported some form of evaluation,<sup>3 4 15 19-21 25 34 35</sup> with 28% collecting feedback from PRPs on their involvement. Regular discussions and evaluations of the quality and impact of PRPs' collaboration and contributions were reported to enhance understanding, satisfaction and impact, allowing for adjustments and improvements as needed.<sup>4 5 37 60</sup> Some tools were reported for monitoring such as the Patient-Centered Outcomes Research Institute conceptual framework, an evaluative framework for research engagement,<sup>19</sup> surveys to evaluate the impact of PRPs in the project,<sup>3 26</sup> the Public Involvement Impact Assessment Framework Guidance,<sup>53</sup> and the Guidance for Reporting Involvement of Patients and the Public.<sup>25 34</sup>

### Recognition, compensation and acknowledgement of PRPs

Recognising, compensating and acknowledging the contributions of PRPs during their involvement in a scientific project

**Table 6** Reported training content for researchers and PRPs

Soft skills	Training content for researchers	Training content for PRPs
General training	<ul style="list-style-type: none"> <li>▶ Provide guidance on how to engage lay audiences in research</li> </ul>	<ul style="list-style-type: none"> <li>▶ Guidance and support from experienced PRPs<sup>19</sup></li> <li>▶ Individual support and training provided upon request<sup>25</sup></li> </ul>
Communication skills training	<ul style="list-style-type: none"> <li>▶ Exercises to improve communicating research findings to non-scientists</li> <li>▶ Strategies to avoid jargon and define terms for better understanding of research discussions by PRPs</li> <li>▶ Practising communication skills: respectful dialogue, active listening and knowledge checks for successful PRP engagement</li> </ul>	<ul style="list-style-type: none"> <li>▶ Communication skills training<sup>45</sup></li> </ul>
Education	<ul style="list-style-type: none"> <li>▶ Understanding the advantages of involving PRP in research</li> <li>▶ Understanding collaborative research principles</li> </ul>	<ul style="list-style-type: none"> <li>▶ Training courses on their own<sup>45</sup></li> <li>▶ One-on-one training with mentors<sup>38</sup></li> <li>▶ Individual support and training tailored to needs of the individual or specific research activities<sup>4 15 24</sup></li> <li>▶ Intensive training programme in research for PRPs, for example, 2-day training as a PRP in research<sup>63</sup></li> <li>▶ Preparatory course for PRPs, for example, special training by the German League against Rheumatism<sup>45</sup></li> <li>▶ Continued education opportunities for PRPs, for example, courses through EULAR School of Rheumatology<sup>5 69</sup></li> <li>▶ Educational webinars, workshops and feedback sessions, for example, OMERACT,<sup>5</sup> EUPATI</li> </ul>
Resources	<ul style="list-style-type: none"> <li>▶ Resources available on websites for researchers</li> </ul>	<ul style="list-style-type: none"> <li>▶ Online training on patient participation in research<sup>62</sup></li> <li>▶ Reference materials for PRP involvement in research, for example, EULAR patient involvement reference cards<sup>51 70</sup></li> <li>▶ Glossaries for research terminology, for example, glossaries on NIH and CARRA websites<sup>38</sup></li> <li>▶ Glossary and lay summaries of sessions in conferences or prior to meetings,<sup>25</sup> for example, OMERACT<sup>19</sup></li> <li>▶ Extensive library of engagement training resources, for example, PCORI engagement training materials<sup>38</sup></li> <li>▶ Comprehensive training manual for PRPs,<sup>37</sup> for example, EUPATI</li> </ul>
Confidence building	<ul style="list-style-type: none"> <li>▶ Building confidence in engaging young individuals in research activities</li> </ul>	–
Engagement of PRPs	<ul style="list-style-type: none"> <li>▶ Practising role-playing for the first introduction meetings between PRPs and researchers</li> <li>▶ Identification of opportunities to increase PRP involvement</li> </ul>	–

CARRA, Childhood Arthritis and Rheumatology Research Alliance; EULAR, European Alliance of Associations for Rheumatology; EUPATI, European Patients' Academy on Therapeutic Innovation; NIH, National Institute of Health; OMERACT, Outcome Measures in Rheumatology; PCORI, Patient-Centered Outcomes Research Institute; PRP, patient research partner.

were reported to be essential components of equal and meaningful partnerships.<sup>27</sup>

In the context of recognition, coauthorship was cited as proof of PRP involvement and equality in research collaborations.<sup>5 39</sup> The SLR revealed a growing trend in recognising PRPs through coauthorship in 68% of articles,<sup>2-6 8 15 19-21 23-26 28 29 34 36-40 42 43 45 47-50 52 54 56 58 60 63 65</sup> and acknowledgement in 45% of articles.<sup>3 6 7 25 27 28 34 37 43-45 48 51 53 56-61 63 65-67</sup>

Compensation refers to the payment of salary, wages, honorarium, fees or allowances for the time commitment and expertise of PRPs; this is different from reimbursing PRPs for expenses (eg, travel expenses and accommodation).<sup>49</sup> Non-compensation for PRPs was reported as a limitation and challenge for their effective involvement.<sup>4</sup> While PRPs can opt out of payment, several papers reported that researchers should consider compensation in their budget planning.<sup>2 39 49</sup> Some articles advised that institutions should simplify processes for fair PRP payment, and funders should enable researchers to allocate resources for PRP involvement.<sup>5</sup>

## DISCUSSION

The role of PRPs in rheumatology research has significantly expanded over recent years. The findings of this SLR underscore the important roles and contributions of PRPs in research projects, and the added value of PRP involvement, not only in clinical research, but also in basic, translational, registry and longitudinal observational studies. This review also highlighted current challenges and barriers, and pulled together proposals of strategies to overcome them.

The exact definition and roles of PRPs remain unclear for some researchers. A wide proportion of the reviewed studies had adopted the 2011 EULAR definition of PRP which reflects the global acknowledgement of the importance of PRP involvement in rheumatology research and the need for specific recommendations.<sup>14</sup> PRPs hold a crucial position in recognising and actively integrating the patient perspective, their voice and needs into research decision-making processes. Diverse roles and activities were undertaken by PRPs in this SLR, from research partners to patient advocates, reflecting the many ways PRPs can contribute. Their involvement, as evident in recent papers shaping research priorities, guideline development, and scientific and clinical committees, suggests a trend towards more inclusive and patient-centred research practices.

Our review revealed specific barriers and challenges in communication, training, research processes and collaboration. These challenges highlight difficulties in communication and relationship dynamics during research, the necessity for training and support for both PRPs and researchers, concerns about the research process and its pace, and obstacles in PRP collaboration, including issues of recognition and diversity. Inclusivity and diversity are important topics for future research. To address these challenges effectively, targeted strategies such as fostering open communication, creating a supportive environment, ensuring early and sustained involvement, using a PRP coordinator and providing appropriate training and support for PRPs and researchers are crucial. These findings underscore the ongoing need for refining and implementing these strategies to enhance PRP involvement more efficiently.<sup>26</sup>

A key observation from the SLR is the importance of early and sustained PRP involvement in research projects. Engaging PRPs from the research project's inception ensures that research questions and methodologies are aligned with patients' priorities and perspectives right from the start. Sustained involvement

further reinforces the trust and collaboration between PRPs and researchers, leading to research outcomes that are more relevant and impactful. The OMERACT recommendations proposed that the level and timing of PRP involvement should vary based on the scope and type of project, emphasising adaptability as a key factor for successful involvement.<sup>15</sup>

Evaluation and monitoring are also integral aspects of PRP involvement. This ongoing reflection and feedback process is vital for fostering effective and meaningful PRP involvement in research. Recognition, compensation and acknowledgement of PRPs stand as key elements for fostering a meaningful partnership. Coauthorship serves not only to document the PRP's contribution but also reinforces the idea of collaborative research. Of note, we observed disparity between the involvement of PRPs in research activities versus their acknowledgement as coauthors. This disparity may arise from some PRPs not prioritising or desiring coauthorship, or being unable to participate in producing and writing a research paper due to health-related challenges such as disease flare-ups or fatigue. In ensuring equitable recognition, a collective effort is essential to guarantee that PRPs receive due acknowledgement and compensation for their valuable contributions to scientific research.

Our study has strengths and weaknesses. One important strength of this SLR is that the findings will equip researchers, healthcare professionals and other stakeholders with evidence-based solutions to improve PRP involvement in medical research. To this end, the findings have supported the process of updating the EULAR recommendations for PRP involvement and made them more evidence based.<sup>1</sup> Another strength is the obtention of a more nuanced understanding of the challenges and complexities surrounding PRP involvement in rheumatology research. Furthermore, our study stands out for its comprehensive approach, analysing a broad spectrum of study types, including quantitative and qualitative studies, reviews, opinion pieces and information from websites. The inclusion of various rheumatic musculoskeletal disease conditions, encompassing both paediatric and adult populations, enhances the robustness of our findings. Another notable strength lies in the co-production of this work by three PRPs. The project was initiated and led by a PRP (MdW) who gave the work direction, participated in article screening, article analysis, overall interpretation and manuscript writing. The two other PRPs brought important insights into PRP roles, facilitators and barriers.

A limitation of the study might be the heterogeneity of the included papers. Because of the expected limited reporting of PRP involvement in rheumatology research, we decided to include a diversity of papers in the SLR, varying from qualitative studies, case studies and original research papers to conference reports and opinion articles. This heterogeneity did not allow for any form of meta-analysis, nor for identifying themes that would benefit individual groups of PRPs such as people with rare diseases, children or young adults, or people with different cultural or ethnic backgrounds. Furthermore, quality assessments could not be uniformly applied across all study types. It is important to note that the traditional evidence hierarchy may not be applicable to this SLR, given the expected absence of randomised controlled studies. Despite this, certain papers were assessed to be of high quality of evidence within their respective study types. While the systematic approach ensured a comprehensive gathering of data, there might be relevant grey literature or non-English-language publications that were not included. Another limitation might be the time period of the last 6 years, including data from articles published between January 2017 and January 2023. This time frame was chosen to reflect studies



performed after the 2011 EULAR recommendations were published, taking into account the implementation time gap.<sup>14</sup> Furthermore, the chosen time span resulted in 53 articles which was deemed sufficient for gathering relevant data related to our research questions.

In conclusion, this SLR identified numerous publications reporting on PRP involvement in rheumatology research. Most authors reported that PRP involvement not only enriches the research process but also ensures that research outcomes are more relevant, meaningful and patient centred. However, for this involvement to be genuinely effective, it is essential to address the barriers and challenges that PRPs and researchers are facing. By updating the EULAR 2011 recommendations, based on the findings of this SLR, we can look forward to a future where research is more inclusive, collaborative, and aligned with patient needs and perspectives.

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