EULAR recommendations for the involvement of patient research partners in rheumatology research: 2023 update

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ABSTRACT

Background Since the publication of the 2011 European Alliance of Associations for Rheumatology (EULAR) recommendations for patient research partner (PRP) involvement in rheumatology research, the role of PRPs has evolved considerably. Therefore, an update of the 2011 recommendations was deemed necessary.

Methods In accordance with the EULAR Standardised Operational Procedures, a task force comprising 13 researchers, 2 health professionals and 10 PRPs was convened. The process included an online task force meeting, a systematic literature review and an in-person second task force meeting to formulate overarching principles (OAPs) and recommendations. The level of agreement of task force members was assessed anonymously (0–10 scale).

Results The task force developed five new OAPs, updated seven existing recommendations and formulated three new recommendations. The OAPs address the definition of a PRP, the contribution of PRPs, the role of informal caregivers, the added value of PRPs and the importance of trust and communication in collaborative research efforts. The recommendations address the research type and phases of PRP involvement, the recommended number of PRPs per project, the support necessary for PRPs, training of PRPs and acknowledgement of PRP contributions. New recommendations concern the benefits of support and guidance for researchers, the need for regular evaluation of the patient–researcher collaboration and the role of a designated coordinator to facilitate collaboration. Agreements within the task force were high and ranged between 9.16 and 9.96.

Conclusion The updated EULAR recommendations for PRP involvement are more substantially based on evidence. Together with added OAPs, they should serve as a guide for researchers and PRPs and will ultimately strengthen the involvement of PRPs in rheumatology research.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ In 2011, European Alliance of Associations for Rheumatology (EULAR) published the first set of recommendations for the involvement of patient representatives in scientific projects and defined the role of patient research partners (PRPs).

⇒ The role of PRPs has evolved and the inclusion of PRPs in research has considerably expanded since 2011.

WHAT THIS STUDY ADDS

⇒ The updated recommendations for the involvement of PRPs in scientific projects have become more evidence based and cover subjects such as research type (including basic and translational research), involvement from the research project's inception, the recommended number of PRPs and the support, training and acknowledgement of PRPs.

⇒ These recommendations also address new topics such as the support and training of researchers, the role of a PRP coordinator and the need for regular monitoring and evaluation.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The updated EULAR recommendations for the involvement of PRPs in research will guide researchers and PRPs in enhancing effective partnerships in their research efforts.

⇒ The ultimate benefit relates to the conduct of health research that better meets the needs of patients, which is likely to result in improved long-term health outcomes.

INTRODUCTION

The benefits of involving patient research partners (PRPs) in research are increasingly recognised by international organisations such as the WHO and European Medicines Agency (EMA).[1 2] To operationalise patient involvement in research, recommendations and guidelines are useful. In rheumatology, the European Alliance of Associations for Rheumatology (EULAR) has historically been a leader in the field of patient involvement—both for clinical care, teaching

and research.[3] EULAR is built on three pillars: rheumatologists, health professionals and patients. In 2011, EULAR published recommendations for the inclusion of PRPs in scientific projects.[4] PRPs were clearly distinguished from patients or study participants in clinical research. PRPs were defined 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.[4]

These were, to our knowledge, the first recommendations in rheumatology on this subject. Since then, the role of PRPs has significantly changed and expanded within and beyond the field of rheumatology. They are now not only involved in guideline development and clinical research but also in patient-reported outcomes (PRO) development, patient preference studies, research grant application assessment, regulatory processes and international research consortia.[5–9] While the initial 2011 EULAR recommendations have facilitated the implementation of these collaborative partnerships, there are still areas where PRP involvement is limited or absent such as basic and translational research, randomised controlled trials (RCTs), registries and longitudinal observational studies.[10 11] From research projects that were successful or failed in creating collaborative partnerships, we have gained more knowledge about the challenges and facilitators of PRP involvement.[7 12 13] These challenges revealed gaps where the 2011 recommendations fall short and where an update would be beneficial.

In addition, the 2011 EULAR recommendations prompted the establishment of national[14] and international PRP networks[12 15–17] including over 100 experienced and trained PRPs. EULAR has been proactive in supporting PRP involvement through the development of an online course for PRPs and facilitating an active study group for collaborative research that gathers twice a year.[18] However, the existing recommendations did not address monitoring, evaluation or reporting of lessons learnt regarding the collaboration between PRPs and researchers, which now appear indispensable for increasing our knowledge about PRP involvement and enhancing the implementation of PRPs in rheumatology research.

Finally, while the 2011 recommendations were largely based on expert opinion, since then an increasing number of studies exploring PRP involvement have been published, that now inform this update of the recommendations and provide more evidence.

Therefore, the aim of the current task force was to update the 2011 EULAR recommendations.

The target audience for these recommendations are researchers, PRPs, health providers, journal editors, research funders, ethical review boards and other stakeholders in the field of adult rheumatology and beyond.

METHODS

According to our aim, we updated the 2011 EULAR recommendations for PRP involvement in research, formulated a set of overarching principles (OAPs) and developed a research agenda for the future. Of note, the scope of these recommendations is specific to the role of patients as collaborative partners in research, which is different from other roles of patients such as study participant, observer, informant or advisor. However, the updated recommendations should always consider the complementary role of PRPs in the broader context of patient and public involvement (PPI).

Box 1 Themes of the systematic literature review

1. Definition of patient research partners (PRPs).
2. Participation, roles, and activities of PRP.
3. Added value of PRPs.
4. Selection and recruitment of PRP.
5. PRP experience and feedback.
6. Facilitators and the supportive role of the investigator.
7. Training or education of PRP and researchers.
8. Recognition of PRPs.
9. Monitoring of PRP involvement.

We followed the updated EULAR Standardised Operational Procedures.[19] The process took place between October 2022 and June 2023 and included an online task force meeting, a systematic literature review (SLR) and an in-person second task force meeting to formulate OAPs and recommendations.

Steering group and task force composition

After the approval of this project by EULAR (September 2022), the steering group, comprising the convenor (MdW), an EULAR methodologist (LG), a junior methodologist (PS), a fellow and EMEUNET member (KA), a health professional (JP) and two PRPs (HB and CZ), had regular meetings between October 2022 and September 2023. They prepared the task force meetings and supported the SLR. Two EMerging EUlar NETwork (EMEUNET) members (ME and DB) joined the Steering Group after the first task force meeting. Including the steering group members, the task force comprised 13 researchers (6 were EMEUNET members) with backgrounds in basic, translational, clinical and social sciences, 2 health professionals and 10 PRPs with Rheumatic and Musculoskeletal Diseases (RMDs), of whom 2 represented young people. Members came from 15 European countries and Canada. The PRPs represented five RMDs.

Process

The first task force meeting was held online (December 2022) and resulted in a set of research questions that focused on nine themes (box 1).

To address these research questions in a data-driven manner, an SLR was performed for the period 2017–2022 in rheumatology journals.[20] The literature assessed in the SLR was complemented by information found on the British, European and American websites of three specialties (oncology, cardiology and diabetology) and those of Food and Drugs Administration and EMA. In addition, the following guidelines were consulted to answer specific questions about training, involvement of PRPs in translational research, and remuneration of PRPs: National Institute for Health and Care Research guidelines in the UK, guide on patient partnerships in rare disease research projects and the European Patients' Academy on Therapeutic Innovation (EUPATI).[21–23] Finally, the research questions mandated an additional scoping review on the involvement of PRPs in translational and RCT studies in rheumatology in the last years.[24] All findings were presented at our second task force meeting to inform the update of the recommendations.

Based on the literature, the steering group proposed tentative OAPs. Because these had not been developed for the 2011 recommendations, they were formulated here. The existing

Table 1 Grid for determining the grade of recommendations

Grade of recommendation	Number of SLRs and/or high-level or medium-level studies
A	One high-level SLR or five or more consistent high-level studies
B	Four high-level studies
C	Three high-level studies or one high-level and two medium-level studies
D	Two or less high-level studies, or inconsistent or inconclusive studies of any level

SLR, systematic literature review.

recommendations were thoroughly revised and new recommendations were proposed.

The second task force meeting took place in Amsterdam, Netherlands (April 2023) as a 1-day meeting with 24 members participating in person and one member online (DPR). Prior to the meeting, an introduction session was held to inform the task force about the applied methodology and to summarise the findings from the SLR. This session was attended by 21 task force participants. During the task force meeting, the SLR findings were presented followed by discussions and voting on each of the new OAPs and revised recommendations. The votes were considered as consensus if 75% agreement was reached in the first round, then if needed for a second round of voting, 66% and 50% in case of a third round.[25] At the end of the meeting, the evidence for three new recommendations was presented and discussed followed by voting on the respective statements.

Because our recommendations are not focused on (pharmaceutical) management of RMDs, we did not use the Oxford framework for assessing the strengths of our recommendations. We decided to base our GoR only on the quality assessment of four categories of articles from our SLR[20]: qualitative, reviews, cross-sectional and mixed-methods studies. For the first three types of studies, the Critical Appraisal Skills Programme (CASP) checklist was used (n=13)[26] and for the mixed-methods studies we used the Mixed Methods Appraisal Tool (MMAT) checklist (n=6).[27] The quality assessment for the 19 articles was classified by the steering group on the basis of consensus as low, medium or high, based on the percentage of items in the quality checklist which were satisfied and the importance of the items in this checklist. The respective cut-offs were the same for the four categories: 25% or lower was considered low, between 25% and 75% was considered medium and more than 75% was considered high.

For determining the GoR, we developed the following grid, based on the LoE of the 19 papers (table 1). Of note, only studies that recommended a theme (box 1) or confirmed its importance for consideration were included.

Finally, following the second task force meeting, the task force members were invited by email to indicate anonymously their level of agreement with the 5 OAPs and 10 recommendations on a Likert scale between 0 (no agreement) and 10 (full agreement).

RESULTS

The task force derived five new OAPs, six existing recommendations were updated significantly (#1, 2, 4,5, 8, 10), one recommendation was kept unchanged (#3), two were combined into one (#4) and three new recommendations were formulated (#6, 7, 9). The LoE allowed us to obtain moderate GoR (A–D). Agreement with the OAPs and recommendations was high (table 2).

Table 2 Overarching principles and recommendations

Overarching principles	GoR	LoA
A. Patient research partners (PRP) provide input to research, through active collaboration as equal partners with researchers.	n.a.	9.96±0.2
B. PRPs are persons with an RMD who provide input to research, based on their experiential knowledge and expertise.	n.a.	9.92±0.4
C. Informal caregivers can provide input to research, complementary to the patients' lived experience.	n.a.	9.36±1.1
D. PRPs add value and relevance to all types of research; their involvement benefits patients, researchers and PRPs.	n.a.	9.68±0.6
E. Open, transparent communication, trust, respect and willingness to learn from each other are key factors for equal and successful collaboration between PRPs and researchers.	n.a.	9.96±0.2
Recommendations	**GoR**	**LoA**
1. PRPs should be involved in all types of research, including basic, translational and clinical research.	C	9.16±1.3
2. Researchers should involve PRPs from the inception of a research project and throughout all its stages.	B	9.68±0.6
3. A minimum of two PRPs should be involved in each project.	D	9.56±0.7
4. Recruitment of PRPs should be based on a clear and agreed-upon description of mutual roles and responsibilities and should aim for diversity and inclusivity.	C	9.96±0.2
5. The research team must provide a supportive environment and facilitate the contribution of PRPs to research.	D	9.88±0.3
6. A designated coordinator should support the collaboration of researchers and PRPs.	B	9.36±0.9
7. Researchers should have access to training and support, to achieve effective communication and collaboration with PRPs as equal partners.	D	9.68±0.7
8. PRPs should have access to training relevant to their roles.	A	9.72±0.5
9. Researchers and PRPs should regularly evaluate their collaboration and adjust their way of working when needed.	D	9.76±0.5
10. The contribution of PRPs must be appropriately recognised, including co-authorship when eligible; financial compensation should be considered.	D	9.44±0.9

GoR, grade of recommendation; LoA, level of agreement; n.a., not available; RMD, Rheumatic and Musculoskeletal Diseases.

OVERARCHING PRINCIPLES

PRPs provide input to research, through active collaboration as equal partners with researchers

This first OAP is focused on the role of PRPs and highlights not only the added value that they bring to research, but also two key features which are the terms 'equality' and 'active'. This statement emphasises the distinction between the involvement of PRPs and the use of patient consultation strategies. PRPs are not study participants, but people who join research teams to provide their knowledge, skills, experiences and expertise throughout the research cycle. There is a wealth of evidence that shows that research projects benefit from this kind of input.[28–30] The term equality refers to the call to researchers to involve PRPs in a process of shared decision-making; active collaboration refers to the concept of meaningful involvement which includes genuine dialogues and efforts to avoid tokenism.

PRPs are persons with an RMD condition who provide input to research, based on their experiential knowledge and expertise

The first recommendations provided a definition for the role of PRPs.[4] Because this role has evolved, it was deemed necessary to broaden the definition to enable its use in other research contexts than a guideline task force. Our task force agreed to formulate the definition as an OAP and removed reference to the added value of a PRP and to the phase of the study which are now part of OAP #D and recommendation #2, respectively.

Experiential knowledge can be described as the articulated personal experience of living with an RMD, and knowledge obtained from using the healthcare system.[31] Synonyms for experiential knowledge are 'patient story' or 'lived experience'. Experiential expertise refers to the collective articulated experience of PRPs and includes awareness of the heterogeneity of the patients' perspective, insights into patients' needs and preferences, and some lay knowledge of research.[31] Expertise in PRPs can be gained over time through experience in research studies as well as through education and training to improve PPI.

Of note, it is not the primary task of PRPs to fully represent the target population. Representativeness is a responsibility of the entire research team and can be obtained through the use of a variety of consultation methods, such as mixed research methods including qualitative studies, Delphi methods or surveys to expand the input from a larger group of people with the condition under investigation.[32–34] PRPs may bring specific knowledge and expertise in developing effective strategies for PPI in a study. In addition, researchers may also consider inviting representatives of patient organisations.

Informal caregivers can provide input to research, complementary to the patients' lived experience

Informal caregivers (also termed carers) are people who are not health professionals but persons who provide ongoing assistance with activities of daily living or social support to a person with a chronic condition or disability, often without professional education and usually without payment.[35] This person is often a family member but can also be a (close) acquaintance. The task force concluded that a caregiver is not a person with lived experience of the condition and therefore cannot fulfil the role of PRP, with the exception of paediatric rheumatology in which it is justified that a parent of a child with an RMD takes on the role of a PRP and brings their child's perspective to the table.

Nevertheless, the task force acknowledged that carers have an independent perspective that can add value to research projects: 'Caregivers have a different lived experience and potentially different concerns than that of a patient so both perspectives should be included when possible'.[36] Because this perspective is complementary to that of PRPs, the task force agreed to formulate this separate OAP on the potential role of informal caregivers.

PRPs add value and relevance to all types of research: their involvement benefits patients, researchers and PRPs

There is a fast-growing number of publications that confirm the added value of PRP involvement in research.[37] PRPs bring experiential knowledge and expertise to research which enhances the relevance and applicability of research findings and improves its impact.[38] PRPs benefit from collaboration because they become more knowledgeable about their conditions, may acquire increased self-confidence and practical skills, experience fulfilment and satisfaction, and gain more insights into research.[12 39 40] Moreover, researchers benefit from PRP involvement too. They obtain a better understanding of research priorities and needs of the community, gain new ideas and become more motivated and focused when being regularly in close contact with someone with the condition under research.[41] They see the implications of their work in real-life, PRPs help them obtain a more holistic view of people with RMDs, and learn to explain research concepts and findings in plain language that is understandable by patients and the general public.[36 41] Finally, at a societal level, PRP involvement increases trust, credibility and accountability of research in the community, improves relationships between researchers and other stakeholders and may ultimately also lead to improved outcomes.[42 43] This is a brief summary of the identified benefits. More illustrative examples can be found in the companion SLR.[20]

Open, transparent communication, trust, respect and willingness to learn from each other are key factors for equal and successful collaboration between PRPs and researchers

Communication is crucial to establish successful and equal relationships.[20] Each research project is unique and needs clear communication about the expectations of all team members.[44 45] Based on the SLR and the expert opinion of the task force members, factors such as trust, respect, transparency and colearning were included in the final OAP.

During the task force meeting, the discussion focused on the meaning of 'respect' and 'colearning'. It was argued that 'listening to each other' and the willingness to open oneself to the perspective and experiences of others, is a critical component of open communication and reducing power imbalances. 'Willingness to learn from each other' was, therefore, accepted as an improved explanation of the concept originally referenced as 'colearning'. Respect is a principle that not only relates to communication, but is essential for building equal partnerships and collaboration, and thus is integral to this statement.

Finally, the difference between 'open' and 'transparent' communication was explained by emphasising the personal dimension in the first, and the more 'formal' component in the latter. Being clear about mutual expectations and limitations and providing honest feedback to each other when things are not going as envisioned, relates to open communication. Examples of transparent communication are being clear about rights and responsibilities, deadlines for tasks, procedures for communication, available support for PRPs and reimbursement policies.

RECOMMENDATIONS

In the following section, each recommendation will be explained in detail, supported by the identified evidence and examples when appropriate.

PRPs should be involved in all types of research, including basic, translational and clinical research

Task force members, reflecting current thinking, considered that there is a need to adjust the 2011 recommendation that read: 'Participation of PRPs is strongly recommended for clinical research projects and for the development of recommendations and guidelines and should be considered for all other research projects'.[4] Based on the reported multiple benefits of PRP involvement,[10 41] the task force concluded that PRPs should be included in all types of research. They saw no need to distinguish between clinical research, guideline development and other types of research. They felt value in emphasising that PRP involvement is also possible in types of research in which PRPs are often absent, such as basic and translational research[24 41] as well as clinical trials, observational studies and registries.[10]

The task force is aware that the new phrasing is aspirational. Indeed, guidance for researchers on how to involve patients is scarce, especially in basic research,[46] and examples of good practice are limited.[24 41 47]

Feasibility of successful recruitment is a concern, given the reported difficulties in identifying PRPs and the risk of overburdening of existing PRPs. The task force felt the current wording would allow researchers and PRPs to tailor the intensity of PRP involvement to the type of research and/or the available resources.

Researchers should involve PRPs from the inception of a research project and throughout all its stages

The SLR showed strong evidence for the benefits of early PRP involvement[39 48 49] as well as prolonged engagement throughout the duration of the research.[37 44 50] Overall, 30% of the studies reported PRP involvement during all stages of the project including conception of the research questions, study design, data collection, interpretation and dissemination.[20] For PRPs, involvement throughout the lifetime of a research project represents a commitment which needs to be clearly stated upfront, and although PRPs are expected to stay involved during the entire research process, the timing and intensity of that involvement may vary, dependent on the scope and objectives of the research, the type of research and personal factors of the researcher(s) or the PRP(s).[51]

A minimum of two PRPs should be involved in each project

There is a strong evidence that having more than one PRP is beneficial and that an ideal number of PRPs depends on the research context.[20] The SLR showed that the number of PRPs included in projects varies depending on the size and type of research. Having more than two PRPs can prevent imbalances in power between the PRPs and the researchers; it encourages PRPs to express their opinions, even if this means disagreeing with a researcher.[52] Thus, the task force decided not to change the 2011 recommendation and to advise researchers, in line with the previous recommendation, to tailor the number to the needs of the study. There should be two PRPs as a minimum and more when needed because of the wish for more diversity in knowledge and expertise, or because of the expected workload and to avoid overburdening.

Recruitment of PRPs should be based on a clear and agreed on description of mutual roles and responsibilities and should aim for diversity and inclusivity

The task force combined the 2011 recommendations #4 and #5. In the new formulation, the role description should be the product of cocreation by the researcher, PRP-coordinator and/or the PRPs and reflect mutual expectations. It should contain a description of the activities and responsibilities of the PRPs as well as those of the research team. In addition, the recruitment process should foster diversity and inclusivity.[34 39 53] This is particularly important where PRP involvement is needed to develop effective recruitment strategies and formulate fair inclusion and exclusion criteria to reach these goals. Useful methods for improving diversity in PPI research exist.[53 54]

The task force reviewed the 2011 recommendation about the selection of PRPs based on required competencies. The SLR findings demonstrated a wide range of reported competencies that were strongly dependent on the role of the PRPs, the (disease) stage and experience of the PRP, and the kind of research activity.[31] The competencies varied from language skills, research knowledge and mobility to education, motivation, communication skills and PRP experience. The task force decided to remove any reference to competencies from the recommendation and to highlight the relevance of the research context for determining the recommended competences. The SLR demonstrated that there is no evidence for one preferred recruitment strategy over any other.[20] Researchers reported different ways of recruitment such as partnering with charities or patient and advocacy organisations, social media, community outreach and through health professionals or personal contact.[20]

The research team must provide a supportive environment and facilitate the contribution of PRPs to research

The task force reached a consensus that the facilitation and support of PRPs should be a shared responsibility among all members of the research team. Collaborative research is all about 'enabling PRPs to make meaningful contributions' and requires, therefore, attention to the special needs for support depending on the type of RMD and the associated symptoms. Accessibility, making sure physical and online spaces are providing the right support, is an important condition for successful collaboration. Other potential conditions are, for instance, the need for a personal assistant, lay summaries, organised transfers or sufficient breaks during meetings. In many cases, fellows and junior researchers work closely together with PRPs and should address these conditions while senior researchers facilitate PRP involvement from a distance.[55] Therefore, early career researchers should address PRP's personal needs, recognise fatigue, establish realistic deadlines, write summaries in plain language, consider the needs of PRPs for whom English is not their first language[7 53 56] and invite PRPs to give their perspective; senior or established researchers are generally responsible to facilitate PRP involvement by establishing optimal circumstances, resources and environments for sustainable involvement of PRPs and removing external, often institutional barriers, for instance, ensuring fair compensation for PRPs.[55]

It was discussed whether support (#5) and training (#8) should be combined in one recommendation. However, the task force decided to keep them separated to emphasise the importance of both kinds of facilitators.

A designated coordinator should support the collaboration of researchers and PRPs

Over the last decade, we witnessed the emergence of the PRP coordinator role.[8 57 58] A PRP coordinator was reported or

Box 2 Potential tasks and responsibilities of a patient research partner (PRP) coordinator

⇒ Recruit and select PRPs.
⇒ Match PRPs with requests from researchers.
⇒ Support the alignment of expectations.
⇒ Organise education and support of PRPs and researchers.
⇒ Facilitate communication.
⇒ Moderate (small) group discussions.
⇒ Organise logistics around PRP involvement such as booking travel and accommodation, and arranging reimbursement.
⇒ Mentor and support younger and less-experienced PRPs.
⇒ Assist researchers at any stage of the research regarding PRP involvement.
⇒ Assist PRPs in their dialogue with employers—providing help in certifying PRPs voluntary involvement in Rheumatic and Musculoskeletal Disease community work.
⇒ Monitoring of the evaluations of PRPs contribution and impact on the project.

advised in 29% of the articles included in the SLR, and in all cases seen as an important facilitator in reducing the chances of tokenism. The PRP coordinator played a major role in the areas of logistics, information, communication and mediation. The SLR provides a comprehensive overview of the activities of the PRP coordinator (box 2).[20]

This role can be taken up by a research team member or by one of the PRPs but can also be positioned within a patient organisation or academic institution. In most cases, the PRP coordinator is responsible for adequate communication between PRPs and researchers, matching PRPs with new research projects and ensuring continuity and sustainable partnerships.[7 8 59] An example of a new task for PRP coordinators is to provide a 'certificate of attendance' after meetings. For some PRPs, such a certificate is important to enhance the dialogue with employers. PRPs may need to take time off from work and a certificate demonstrates that a person is involved in voluntary and important work for the community of people with RMDs so that future involvement is looked on favourably.

In one study included in the SLR, the PRP coordinator was expected to take the lead in setting up meetings and ensuring that ways of communication such as video calling were accessible to PRPs.[39] The PRP coordinator can also facilitate initial discussions to align mutual expectations.[39]

Task force members emphasised that this new role may enhance the implementation of OAP #E on communication, trust and respect. A special warning is justified here: the presence of a PRP coordinator should never replace the responsibility of the research team to ensure adequate support for PRPs or the direct dialogue between researchers and PRPs (see recommendation #5).

Researchers should have access to training and support, to achieve effective communication and collaboration with PRPs as equal partners

The SLR revealed that both PRPs and researchers benefit from (peer-)mentoring, education and training, which was reported or advised in 34% of the articles. The SLR resulted in a list of potential topics for training content, such as communication with PRPs, and how to recruit, select and support PRPs in research studies (box 3).[6 60 61]

There was a debate about the wording with some members of the task force in favour of 'should receive support and training' and others of 'should have access to support and training'. In the end, the wish to homogenise this *statement* with the formulation on the same topic for PRPs (#8), the task force chose the less stringent version.

The training and support, although currently not broadly available, could come from different sources, for instance, EULAR, patient organisations or academic/research institutions. Implementation of this recommendation is highly dependent on the endorsement by the existing leadership of these organisations.[62]

PRPs should have access to training relevant to their roles

Our SLR provided strong evidence that education and training of PRPs increase the quality of the collaboration with researchers.[20] In almost half of the publications, training was either advised (21%) or provided (25%). There is a growing supply of educational opportunities.[63 64] In 2022, the first EULAR online course for PRPs started, and more programmes are available or in development on national level. These training opportunities are provided by different stakeholders. PRPs have a right to access training if they wish, and it is no longer the principal investigator exclusively responsible for organising this. For this reason, the task force decided to adjust the 2011 recommendation by making access to training mandatory. Content of potential courses can be general, such as the EULAR course for PRPs (box 4),[65] as well as tailored to the role and needs of the individual PRP in a specific research context, such as the EUPATI course for patient representatives involved in drug development and regulatory processes[64] or the Outcome Measures in Rheumatology (OMERACT) e-learning modules for PRPs involved in core-outcome set development.[66]

Researchers and PRPs should regularly evaluate their collaboration and adjust their way of working when needed

At the first meeting, the task force requested to explore the need for adequate monitoring and evaluation of PRP involvement in the literature. The results showed that 21% of papers reported or advised a kind of evaluation of PPI. One of the frequently reported challenges for researchers is the measurement of impact of PPI.[50] In addition, PRPs regularly report lack of feedback on their contributions.[8] During the second meeting, the task force discussed the difference between monitoring and evaluation. Monitoring was seen as a way to assess the level of compliance with the EULAR recommendations: how were PRPs recruited, at what stage, how many, and the kind of support and training they received. Evaluation focused on the experiences of the

Box 3 Topics for the training of researchers

⇒ Frameworks for collaboration.
⇒ Communicating with patient research partners (PRPs).
⇒ Different roles of patients in the context of Rheumatic and Musculoskeletal Disease research.
⇒ Recruitment and selection of PRPs.
⇒ Methods of enhancing equity, diversity and inclusion.
⇒ Involving PRPs in all parts of the research cycle.
⇒ Support of PRPs during a study and preventing overburdening of PRPs.
⇒ Compensation and acknowledgement of PRPs.

Box 4 Topics of the European Alliance of Associations for Rheumatology online course for patient research partners (PRPs)

⇒ Principles of collaborative research.
⇒ Basic epidemiology.
⇒ Outcome measures in rheumatology.
⇒ Critical appraisal of literature.
⇒ Development of recommendations.
⇒ Researcher–PRP communication.
⇒ Medicine development and market authorisation.
⇒ Health economics in rheumatology research.
⇒ Reviewing research grant applications.
⇒ Dissemination of scientific information to patients.
⇒ Patient involvement in laboratory research.
⇒ Core outcome set development and the Outcome Measures in Rheumatology (OMERACT) initiative.

people involved: were they satisfied with the collaboration, were expectations met and what was the impact of the PRP involvement on the project? The task force emphasised that the collaboration should be the object of the evaluation, and that there could be a particular role for the PRP coordinator to monitor whether these evaluations happen. In the SLR, examples were given of moderators who created a safe environment that enabled genuine dialogue between patients and researchers to enhance mutual understanding. It was concluded that continuous reflection is required by all to guarantee that obstacles are removed, and doubts expressed.[67]

The contribution of PRPs should be appropriately recognised, including coauthorship when eligible: financial compensation should be considered

The SLR showed that the number of PRPs that are acknowledged by coauthorship is growing.[68] If the Vancouver regulations are fulfilled, 'coauthorship is a recognition of the contributions made by patients and is the ultimate proof of equal and meaningful partnerships'.[13 69] PRPs who meet the International Committee of Medical Journal Editors (ICMJE) criteria are eligible for authorship. If they do not fulfil these criteria or choose not to accept authorship, they should be acknowledged. The task force did not see any reason to change this part of the recommendation. However, in many countries, there is a strong call to compensate PRPs for their time and efforts. Over the past years, several patient and research organisations have developed payment structures to acknowledge the substantial contributions that PRPs provide to research. Some projects are extremely time-consuming. For attending a 2-day annual research meeting, reviewing a series of grant applications or being involved in the development of a decision aid or PRO, PRPs may have to take several days off from work or make other sacrifices. The task force felt that, in addition to reimbursement of out-of-pocket expenses, financial compensation for PRPs should be considered. PRPs may decide whether they want to refrain from payment, but researchers should consider financial compensation when developing their research budget.[70] Research institutes should ease the procedures for fair payment of PRPs,[71] and funders should allow researchers to budget for PPI, including payment of PRPs. The NIHR and the Ludwig Boltzmann Gesellschaft have published generic guidelines for remuneration of public contributors.[72–74]

DISCUSSION

We present here the updated recommendations for the involvement of PRPs in scientific projects. Five new OAPs define the roles of PRPs and informal caregivers, describe the added value that PRPs contribute to research and emphasise the importance of trust, respect, and open and transparent communication as critical factors for successful partnerships. Six significantly changed recommendations cover the research type and phases of PRP involvement, and the support necessary for PRPs, training of PRPs and acknowledgement of PRPs contribution. The statement concerning the recommended number of PRPs per project remained unchanged. The task force formulated three new recommendations about the role of a PRP coordinator, the education of researchers and the need for regular evaluations.

Within the EULAR community of People with Arthritis/Rheumatism in Europe, several national members have appointed PRP coordinators, dedicated to recruit, train, support and coordinate the involvement of PRPs in research projects. This new role seems effective for the establishment of sustainable and productive relationships between PRPs and researchers. Publications from national PRP networks[14] as well as from international consortia[8] show that PRPs appreciate having a dedicated person who supports their involvement and acts as a point of contact. For these reasons, the task force formulated a new recommendation (#6) about the appointment of a designated PRP coordinator. The task force highlighted one caveat: research team members should never be released from their responsibility to contribute to a facilitating environment for meaningful collaboration between PRPs and researchers as stated in recommendation #5.

A second new recommendation (#9) calls on researchers and PRPs to regularly evaluate their collaboration. There is a growing number of publications that report surveys or other kinds of formative evaluations that can inform about the current level of PRP involvement in rheumatology research. The 2011 recommendations were cited or mentioned in 50% of the SLR articles. Although the 2011 EULAR recommendations have facilitated the implementation of collaborative partnerships in a variety of research areas, there are still areas where PRP involvement is limited or absent.[24] Evaluation studies are often initiated by principal investigators of international studies and facilitated by the designated PPI or PRP coordinator. However, there is also a need to collect and publish the experiences of PRPs in smaller or single-centre studies. Hitherto, information on the level of implementation of PRP strategies is still lacking, and there is limited understanding of the challenges faced, the nature of the collaboration between PRPs and researchers, its overall impact and instruments for its assessment. A subsequently proposed recommendation on monitoring and reporting did not reach consensus (60%). It was felt that the current updated set of recommendations will help researchers and PRPs to advance PPI. Their implementation will already require additional effort from both researchers and PRPs, and the introduction of mandatory monitoring and reporting of PRP involvement, was considered to be potentially 'overwhelming' and not always feasible. Although a reporting checklist for PPI activities (GRIPP2) exists,[75] completion is time-consuming and not always appropriate for all types of research.

By emphasising the need for more regular evaluation, the task force hopes that this will be an incentive for better reporting of good and unsound practices of PRP involvement in all types of research. By doing so, we might incorporate further evidence for

Box 5 Research agenda

General
Assessment of the level of implementation of patient research partner (PRP) involvement.
Monitoring of patient and public involvement in research and the added value of the GRIPP-2 framework.
Assessing the impact of diverse PRP perspectives on research outcomes.
Exploring power dynamics and the impact of sociodemographic, cultural, regional and financial factors in PRP involvement.
Understanding differences in PRP involvement between sexes/genders.
Reporting of PRP involvement.
Understanding the perspectives and experiences of PRP and researchers engaged in research.
Evaluating the added value of a designated coordinator.
Optimising the interactions between PRP and researchers through the PRP coordinator.
Establishing fair compensation for PRP contributing to research projects.
Delineate the role of informal caregivers as PRP.
Assess the added value of European Alliance of Associations for Rheumatology as an umbrella PRP network of national networks.
Raising awareness on the need of a global approach (directed to all stakeholders) to facilitate PRP involvement.

Education/training
Evaluating educational needs and preferences for courses for PRP and researchers.
Evaluating usefulness of refresher courses for PRP over time.
Assess the added value of different training opportunities/formats for PRP and researchers (eg, Booklets, online training, live training).
Assessing the feasibility and usefulness of an online course for researchers.
Evaluating the role of PRPs in researcher/student training/education.

Basic/translational projects
Assess means of PRP participation in basic and translational projects.
Evaluate specific needs for PRP engaging in basic and translational projects.
Understanding how to stimulate PRP involvement in basic and translational research.
Developing informative materials to guide basic/translational researchers how to effectively communicate and engage with PRP.
Producing materials guiding researchers how to assess the added value of PRP involvement in basic/translational studies.

Clinical studies projects
Evaluate needs for PRP engaging in specific clinical projects (registries, randomised controlled trial, etc).
Assessing barriers and facilitators to PRP involvement in industry led/sponsored research projects.

Implementation
Identifying barriers and facilitators at different levels that may impact PRP involvement.
Assessing implementation models to develop and optimise implementation practices in PRP research
Establishing solid evaluation practices and framework for PRP involvement.

PPI practices in a future update of the recommendations for the involvement of PRPs in rheumatology research.

Implementation of recommendations requires full endorsement, coordinated actions and joint efforts of all stakeholders involved, from research institutions to organisations and funders.[62] Additionally, a better understanding of barriers and facilitators influencing PRP involvement at macrolevel and microlevel is needed for the implementation of the new recommendations. The establishment of national-specific or disease-specific networks of trained PRPs could help increase the number of available PRPs for research projects. Creating more support and education programmes for researchers, as formulated in the new recommendation #7, could stimulate researchers to start collaborating with PRPs. Finally, implementation would certainly benefit from appointing more PRP coordinators (#6) who could assist in creating workable partnerships in which there is no place for tokenistic approaches.

This update of the current recommendations has several strengths in comparison with the original recommendations. First, the new statements are more strongly based on existing evidence. While the original statements were largely expert driven and partly based on a limited scoping review of the literature (with almost no publications on PRP involvement), the current SLR provided findings of 53 articles focused on the involvement of patients as partners in rheumatology research. This enabled us to attribute GoR to all statements, which makes these recommendations the first set of evidence-based recommendations on PRP involvement. Second, a wider and more diverse group of experts (n=25) were involved in the update compared with the 16 persons in 2011.

A limitation of this project might be the wide range of articles that were included in the SLR, varying from original research studies to meeting reports and opinion articles. For this reason, it was a challenge to assess in a uniform way the literature giving us the level of evidence behind each recommendation since the literature was issued from several different types of studies and the quality assessment grids were adapted to each type of study. Here, we chose to apply a semiquantitative assessment to the quality of the articles. This method may be applicable to other consensus groups dealing with diverse literature.

It is fair to say that, despite the fast-growing body of knowledge on PPI, the quantity of literature pertaining to the participation of PRPs continue to lag behind. The reasons for this may be diverse. Researchers are traditionally not expected, let alone rewarded for detailed reporting of PRP involvement and funders may be reluctant to accept reasonable budgets for PRP strategies in the studies they sponsor. Furthermore, journals may not allow for comprehensive reporting of PRP involvement due to limited word counts, although they start to encourage authors to provide information about their PPI strategy during submission, which enhances the awareness of its importance. Another limitation is the difficulty to develop recommendations appropriate both for adult and for paediatric rheumatology, given the specific challenges of young

PRPs. In fact, these recommendations do not address the specific needs and approaches to the engagement of children and young people with RMDs in research. We recognise the need for separate recommendations based on evidence from the field of paediatric rheumatology.

The resulting lack in reporting also reveals many items that belong to the current research agenda around PRP involvement (box 5).

In conclusion, the EULAR recommendations for the involvement of PRPs in scientific projects were successfully updated by adding five OAPs, revising seven recommendations and adding three new recommendations using an evidence-based approach. This is a significant step forward in advancing PRP involvement in research. Importantly, these recommendations provide a framework for the whole rheumatology research community to improve research practices and culture, and foster collaborative research. Moreover, these recommendations may be applicable in other specialties beyond rheumatology. However, challenges remain, such as reporting limitations and lack of evidence regarding the added value of PRPs in specific research projects and the role of a PRP coordinator. Further efforts are needed to address these challenges, gain consensus on the research agenda and fully implement the updated recommendations.

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