

## Online supplementary material

### Supplementary Table 1. Search strategy used for PRP involvement in rheumatology research

Keywords	Search strategy
<b>Patient research partners</b>	("patient research partner"[All Fields] OR "patient research partners"[All Fields] OR "patient research"[All Fields] OR "patient partner"[All Fields] OR "patient partners"[All Fields] OR "patient participation"[All Fields] OR "patient involvement"[All Fields] OR "patient and public involvement"[All Fields] OR "patients and public involvement"[All Fields] OR "user involvement"[All Fields] OR "users involvement"[All Fields] OR "lay member"[All Fields] OR "lay members"[All Fields] OR "patient advisory group"[All Fields] OR "patient engagement"[All Fields] OR "patient organisation"[All Fields] OR "patient organisations"[All Fields] OR "patient organization"[All Fields] OR "patient advisor"[All Fields] OR "patient advisors"[All Fields] OR "patient advocacy"[All Fields] OR "patient advocate"[All Fields] OR "patient expert"[All Fields] OR "patient experts"[All Fields] OR "participatory research" [All Fields])
<b>Rheumatology</b>	<b>AND</b> ((rheumat* OR (rheumatology[MeSH Terms]) OR ("rheumatic diseases"[MeSH Terms]) OR (rheumatic disease[MeSH Terms]) OR (arthritis[MeSH Terms]) OR (musculoskeletal disease[MeSH Terms]) OR (musculoskeletal diseases[MeSH Terms]))
<b>Date</b>	<b>AND</b> (2017:2023[pdat])
<b>Language</b>	<b>AND</b> (English[Language]).

## Supplementary Table 2: Overview of PRP Involvement across Rheumatology and other Key Specialties Websites.

Websites	Specialty	Key findings on PRP involvement
EULAR <a href="http://www.eular.org/pare-patient-research-partners">www.eular.org/pare-patient-research-partners</a>	Rheumatology	<ul style="list-style-type: none"> <li>Strongly endorses the involvement of PRPs in research projects related to RMDs.</li> <li>Advocates for the establishment and use of the PARE network, offering guiding documents to facilitate PRP inclusion in research endeavors.</li> </ul>
GRAPPA <a href="http://www.grappanetwork.org/prp-network/">www.grappanetwork.org/prp-network/</a>	Rheumatology	<ul style="list-style-type: none"> <li>Established a PRP Network in 2012, formalized by 2017, to actively include patient perspectives in the development of guidelines and recommendations for psoriatic disease.</li> <li>Produced a "Patient's Guide to Treatments for Psoriatic Arthritis," authored by members of GRAPPA's PRP team, aimed at both patients and healthcare professionals.</li> <li>Collaborates with organizations like OMERACT and IDEOM to further incorporate patient perspectives in research and guidelines.</li> </ul>
OMERACT <a href="http://www.omeractprpnetwork.org">www.omeractprpnetwork.org</a>	Rheumatology	<ul style="list-style-type: none"> <li>Prioritizes the experiential knowledge of PRPs, explicitly valuing their contributions to research.</li> <li>Provides comprehensive recommendations for PRP involvement, including identification based on experiential knowledge and language skills, and discusses methods to support PRPs, like offering tailored information and meeting invitations.</li> </ul>
ACR <a href="http://www.rheumatology.org">www.rheumatology.org</a>	Rheumatology	<ul style="list-style-type: none"> <li>Runs a Patient Perspectives program and ensures that PRPs are involved in the formulation of clinical guidelines and recommendations.</li> <li>Not explicit information about PRP involvement found on their website.</li> </ul>
FOREUM <a href="http://www.foreum.org/involving_prp_of_m">www.foreum.org/involving_prp_of_m</a>	Rheumatology	<ul style="list-style-type: none"> <li>Incorporates PRPs in its Executive and Scientific committees.</li> <li>Strongly recommends the participation of PRPs in clinical research projects and suggests referring to EULAR documents for best practices, aiming to improve the relevance, quality, and validity of research.</li> </ul>
European society of cardiology <a href="http://www.escardio.org/The-ESC/What-we-do/esc-patient-engagement">www.escardio.org/The-ESC/What-we-do/esc-patient-engagement</a>	Cardiology	<ul style="list-style-type: none"> <li>Establishment of the 2018 ESC patient forum with involvement of patients representatives : <ul style="list-style-type: none"> <li>- in training of physicians</li> <li>- in education of patients</li> <li>- in development of guidelines</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>• Participation of patient representative in meetings (workshops for patients, participation in congress as speakers and co-chairs)</li> <li>• Patient representatives are co-authors and reviewers of papers.</li> </ul>
British cardiovascular society <a href="http://www.britishcardiosociet y.org/about/research">www.britishcardiosociet y.org/about/research</a>	Cardiology	<ul style="list-style-type: none"> <li>• Establishment of the BHF Clinical research Collaborative</li> <li>• Promotion of PPI in grant application</li> </ul>
European Society for Medical Oncology  www.esmo.org	Oncology	<ul style="list-style-type: none"> <li>• Establishment of the patient advocacy track</li> <li>• Involvement of patient representatives in education of the patients</li> <li>• Participation of patient representatives in meetings/congresses</li> </ul>
Diabetes UK  <a href="http://www.diabetes.org.uk/profession als/resources/shared-practice/patient-and-public-involvement">www.diabetes.org.uk/profession als/resources/shared-practice/patient-and-public-involvement</a>	Endocrinology	<ul style="list-style-type: none"> <li>• Promotion of PPI in grant application</li> <li>• Development of guidelines for researchers to involve PPI</li> <li>• Review of the applications by the grant advisory panel</li> </ul>
Food and Drug Administration (FDA) <a href="https://www.fda.gov/patients/learn-about-fda-patient-engagement">https://www.fda.gov/patients/learn-about-fda-patient-engagement</a>	Regulatory agency	<ul style="list-style-type: none"> <li>• Patient focused drug development (PFDD)</li> <li>• Patient representative program</li> <li>• Patient Engagement Advisory Committee (PEAC) and Patient Engagement Collaborative (PEC)</li> <li>• Patient listening session program</li> </ul>
European Medicines Agency (EMA) <a href="#">Patients and consumers   European Medicines Agency (europa.eu)</a>	Regulatory agency	<ul style="list-style-type: none"> <li>• Comprehensive framework for engagement</li> <li>• Collaboration with both individual patient experts and patient organisations.</li> <li>• Patients' and consumer working party</li> <li>• Public engagement department</li> <li>• Patients are members of the management board and scientific committees</li> <li>• Training for patient participants is provided by a comprehensive set of videos and in-house one-day training sessions.</li> </ul>

*ACR: American College of Rheumatology, EMA: European Medicines Agency, EULAR: European Alliance of Rheumatology Associations, FDA: Food and Drug Administration, FOREUM: Foundation for Research in Rheumatology, GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis, OMERACT: Outcome Measures in Rheumatology, OARSI: Osteoarthritis Research Society International, NIHR: National Institute for Health Research.*

The following websites were searched but did not provide any information on the involvement of PRPs: OARSI, American heart association, American society of clinical oncology, American diabetes association, European Foundation for the Study of Diabetes, British Society for Paediatric endocrinology and diabetes.

**Supplementary Table 3. Specific website searches in patient and public involvement about training, involvement in grants and remuneration of PRPs.**

INVOLVE UK guidelines (by NIHR) <a href="http://www.invo.org.uk">www.invo.org.uk</a>	Patient and public involvement	<ul style="list-style-type: none"> <li>• Development of guidelines to involve PPI in research projects</li> </ul>
EUPATI <a href="http://www.eupati.eu">www.eupati.eu</a>	Patient and public involvement	<ul style="list-style-type: none"> <li>• EUPATI Fundamentals: training (co-designed and co-delivered by patients and pharmaceutical experts) about Patient Engagement addressed to professionals in academia and pharmaceutical industry</li> <li>• EUPATI training for patients and patient representatives.</li> <li>• Two EUPATI Patient Expert Training Courses (14 months each)</li> </ul>
Short guide on patient partnerships in rare disease research projects <a href="https://www.ejprarediseases.org/our-actions-and-services/patients-in-research/">https://www.ejprarediseases.org/our-actions-and-services/patients-in-research/</a>	Orphan diseases	<ul style="list-style-type: none"> <li>• Development of a guide to include PPI in research projects</li> <li>• Suggestion that a PRP should be ideally affiliated to a patient organisation or a patient group.</li> </ul>

*EUPATI: European Patients' Academy on Therapeutic Innovation, PPI (Patient and public involvement), UK: United Kingdom.*

**Supplementary Table 4. A total of 53 papers included in the Systematic literature review.**

First author (name)	Year of publication	Title	Journal	Study type	Quality assessment
Studenic P et al [26]	2022	Unmet need for patient involvement in rheumatology registries and observational studies: a mixed methods study.	RMD open	Mixed methods	MMAT: <b>High quality</b>
Haribhai-Thompson J et al [40]	2022	Involving People with Lived Experience as Partners in Musculoskeletal Research: Lessons From a Survey of Aotearoa/New Zealand Musculoskeletal Researchers.	The Journal of orthopaedic and sports physical therapy	Cross-sectional	CASP: <b>High quality</b>
de Wit M et al [25]	2022	Patient involvement in basic rheumatology research at Nijmegen: a three year's responsive evaluation of added value, pitfalls and conditions for success.	BMC rheumatology	Mixed methods	MMAT: <b>High quality</b>
de Souza S et al [35]	2022	Patient and public involvement in an international rheumatology translational research project: an evaluation.	BMC rheumatology	Qualitative	CASP: <b>High quality</b>
Elliott RS et al [58]	2022	Improving communication of the concept of 'treat-to target' in childhood lupus: a public and patient (PPI) engagement project involving children and young people.	BMC rheumatology	Mixed methods	MMAT: <b>High quality</b>
Fox et al [41]	2021	Patient engagement in preclinical laboratory research: A scoping review	EBioMedicine	Scoping review	CASP: <b>High quality</b>
Costello W et al [28]	2020	Laying the groundwork: Building relationships for public and patient involvement in pre-clinical paediatric research.	Health expectations : an international journal of public participation in health care and health policy	Qualitative	CASP: <b>High quality</b>
Birch et al [3]	2020	Development and formative evaluation of patient research partner involvement in a multi-disciplinary European translational research project	BMC Research involvement and engagement	Mixed methods	MMAT: <b>High quality</b>

Morin SN et al [52]	2020	Patient engagement in clinical guidelines development: input from >â€%1000 members of the Canadian Osteoporosis Patient Network.	Osteoporosis international : a journal established as result of cooperation between the European Foundation for Osteoporosis and the National Osteoporosis Foundation of the USA	Mixed methods	MMAT: <b>High quality</b>
Young K et al [48]	2019	Patient involvement in medical research: what patients and physicians learn from each other.	BMC, Orphanet journal of rare diseases	Qualitative	CASP: <b>High quality</b>
Parsons S et al [45]	2018	What do young people with rheumatic conditions in the UK think about research involvement? A qualitative study.	Pediatric rheumatology online journal	Qualitative	CASP: <b>High quality</b>
Leese J et al [49]	2018	Adding another spinning plate to an already busy life'. Benefits and risks in patient partner-researcher relationships: a qualitative study of patient partners' experiences in a Canadian health research setting	BMJ open	Qualitative	CASP: <b>High quality</b>
Gossec L et al [57]	2014	A patient-derived and patient-reported outcome measure for assessing psoriatic arthritis: elaboration and preliminary validation of the Psoriatic Arthritis Impact of Disease (PsAID) questionnaire, a 13-country EULAR initiative	ARD	Cross-sectional	CASP: <b>high quality</b>
de Wit M et al [23]	2013	Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences.	BMJ open	Qualitative	CASP: <b>high quality</b>
de Wit M et al [24]	2013	Facilitating and inhibiting factors for long-term involvement of patients at outcome conferences-- lessons learnt from a decade of collaboration in OMERACT: a qualitative study.	BMJ open	Qualitative	CASP: <b>high quality</b>
Lyng KD et al [59]	2022	Participatory research: a Priority Setting Partnership for chronic musculoskeletal pain in Denmark.	Scandinavian journal of pain	Mixed methods	MMAT: <b>Medium quality</b>

Carr ECJ et al [38]	2019	Co-design of a patient experience survey for arthritis central intake: an example of meaningful patient engagement in healthcare design.	BMC health services research	Qualitative	CASP: Medium quality
Wang H et al [47]	2021	Patient research partner involvement in rheumatology clinical trials: analysis of journal articles 2016-2020.	Annals of the rheumatic diseases	Systematic literature review	CASP: Low quality
Pauling JD et al [65]	2017	Patient participation in patient-reported outcome instrument development in systemic sclerosis.	Clinical and experimental rheumatology	Systematic literature review	CASP: Low quality
Schoemaker CG et al [51]	2023	Matching researchers' needs and patients' contributions: practical tips for meaningful patient engagement from the field of rheumatology.	Annals of the rheumatic diseases	Qualitative	NS
Richards D et al [50]	2022	Identifying potential barriers and solutions to patient partner compensation (payment) in research	BMC Research involvement and engagement	Qualitative	NS
Del Gaizo V et al [39]	2022	Patient Engagement in Pediatric Rheumatology Research.	Rheumatic diseases clinics of North America	Opinion article	NS
Mikdashi J [22]	2022	The Meaningful Role of Patients, and Other Stakeholders in Clinical Practice Guideline Development.	Rheumatic diseases clinics of North America	Opinion article	NS
Jongsma KR et al [62]	2022	Establishing a multistakeholder research agenda: lessons learned from a James Lind Alliance Partnership.	BMJ open	Opinion article	NS
Bywall KS et al [67]	2022	Functional capacity vs side effects: treatment attributes to consider when individualising treatment for patients with rheumatoid arthritis.	Clinical rheumatology	Qualitative not focused on PRP	NS
Ecem Esen et al [54]	2022	The Your Rheum story: involvement of young people in rheumatology research	BMC rheumatology	Case study	NS
Goel [21]	2021	Enhancing patient research partner engagement: Research in psoriatic arthritis	Best Practice & Research Clinical Rheumatology	Opinion article	NS
Schöpf-Lazzarino AC et al [46]	2021	Involving patients as research partners exemplified by the development and evaluation of a communication-skills	Zeitschrift für Rheumatologie	Case study	NS

		training programme (KOKOS-Rheuma).			
Van der Elst K et al [55]	2021	More than just chitchat': a qualitative study concerning the need and potential format of a peer mentor programme for patients with early rheumatoid arthritis.	RMD open	Qualitative, not focused on PRP	NS
Shoop-Worrall SJW et al [61]	2021	Nothing about us without us: involving patient collaborators for machine learning applications in rheumatology.	Annals of the rheumatic diseases	Opinion article	NS
O'Sullivan DP et al [56]	2021	GRAPPA Patient Research Partner Network: Update to the GRAPPA 2020 Annual Meeting.	The Journal of rheumatology	Meeting report	NS
Golenya R et al [42]	2021	How to improve diversity in patient and public involvement.	British journal of hospital medicine (London, England : 2005)	Opinion article	NS
Taylor J et al [2]	2021	Making the patient voice heard in a research consortium: experiences from an EU project (IMI-APPROACH).	Research involvement and engagement	Case study	NS
Goel [27]	2020	Conducting research in psoriatic arthritis: the emerging role of patient research partners	Rheumatology (Oxford, England)	Opinion article	NS
de Wit M et al [44]	2020	Patient engagement in health technology assessment (HTA) and the regulatory process: what about rheumatology?	RMD open	Opinion article	NS
de Wit M et al [4]	2019	Practical guidance for engaging patients in health research, treatment guidelines and regulatory processes: results of an expert group meeting organized by the World Health Organization (WHO) and the European Society for Clinical and Economic Aspects of Osteoporosis, Osteoarthritis and Musculoskeletal Diseases (ESCEO).	Aging clinical and experimental research	Recommendations	NS
de Wit M et al [5]	2019	Unique role of rheumatology in establishing collaborative relationships in research.	Annals of the rheumatic diseases	Opinion article	NS



		Past, present and future of patient engagement.			
Schopf AC et al [6]	2019	Development and Formative Evaluation of a Communication Skills Training Program for Persons with Rheumatic and Musculoskeletal Diseases.	Health communication	Case study	NS
Belton J et al [20]	2019	Patients as Partners in Research: It's the Right Thing to Do.	The Journal of orthopaedic and sports physical therapy	Opinion article	NS
Schoemaker CG et al [63]	2018	Dutch juvenile idiopathic arthritis patients, carers and clinicians create a research agenda together following the James Lind Alliance method: a study protocol.	Pediatric rheumatology online journal	Study protocol	NS
Goel N et al [64]	2018	The Patient Research Partner Network Matures: A Report from the GRAPPA 2017 Annual Meeting.	The Journal of rheumatology.	Meeting report	NS
Helliwell PS et al [69]	2017	Prologue: 2016 Annual Meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA).	The Journal of rheumatology	Meeting report	NS
Goel N et al [66]	2017	Tackling Patient Centricity: A Report from the GRAPPA 2016 Annual Meeting.	The Journal of rheumatology	Meeting report	NS
Goodman SM et al [60]	2017	Clinical Practice Guidelines: Incorporating Input From a Patient Panel.	Arthritis care & research	Report	NS
de Wit M et al [36]	2017	Successful Stepwise Development of Patient Research Partnership: 14 Years' Experience of Actions and Consequences in Outcome Measures in Rheumatology (OMERACT).	The patient	Opinion article	NS
Pollock J et al [7]	2017	Patient and researcher perspectives on facilitating patient and public involvement in rheumatology research.	Musculoskeletal care	Meeting report	NS
Kirwan JR et al [19]	2017	Emerging Guidelines for Patient Engagement in Research.	Value in health: the journal of the International Society for Pharmacoeconomics and Outcomes Research	Recommendations	NS
Brett J et al [68]	2017	Reaching consensus on reporting patient and public involvement (PPI) in	BMJ open	Recommendations	NS

		research: methods and lessons learned from the development of reporting guidelines.			
Leese J et al [53]	2017	Evolving Patient-Researcher Collaboration: An Illustrative Case Study of a Patient-Led Knowledge Translation Event.	Journal of participatory medicine	Meeting report	NS
Tunis SR et al [29]	2017	Engaging Stakeholders and Promoting Uptake of OMERACT Core Outcome Instrument Sets.	The Journal of rheumatology	Meeting report	NS
Cheung PP et al [15]	2016	Recommendations for the Involvement of Patient Research Partners (PRP) in OMERACT Working Groups. A Report from the OMERACT 2014 Working Group on PRP.	The Journal of rheumatology	Recommendations	NS
de Wit M et al [43]	2016	Let's Talk about Inclusion: A Report on Patient Research Partner Involvement in the GRAPPA 2015 Annual Meeting.	The Journal of rheumatology	Meeting report	NS
de Wit M et al [37]	2014	Patient participation in psoriasis and psoriatic arthritis outcome research: a report from the GRAPPA 2013 Annual Meeting.	The Journal of rheumatology	Meeting report	NS

NS: Not scored.

Cross-sectional observational studies were assessed using the STROBE evaluation form; mixed methods studies using the mixed methods appraisal tool (MMAT); qualitative studies using the CASP checklist and reviews (SLR and scoping reviews) using the PRISMA. Qualitative studies without a focus on PRP were not assessed for quality (n=2).

**Supplementary Table 5. Type of studies included in the SLR.**

Type of study	n (%)	Quality assessment
Qualitative	12 (23%)	Yes*
Mixed methods	6 (11%)	Yes
Review (SLR or scoping)	3 (6%)	Yes
Cross-sectional	2(4%)	Yes
Opinion	11(21%)	No
Report	10 (19%)	No
Recommendation	4(8%)	No
Case study	4(8%)	No
Study protocol	1(2%)	No

\*excluding 2 qualitative articles not focused on PRPs.

**Supplementary Table 6. Analysis of qualitative data according to the principles of thematic content analysis.**

The qualitative analysis involved extracting pertinent information from the text of each study and developing a coding scheme to categorize the approaches to patient involvement. Extracted data were then organized into conceptual categories.

	Extracted data ordered in conceptual categories
a	a narrative description detailing the roles, activities, added values, experiences, and feedback from PRP in the included studies
b	a narrative overview of the PRP selection process, the types of training provided, and the recognition they received
c	a narrative account of the researcher's role and the training they underwent
d	a narrative overview of the potential PRP coordinator's role, along with details on the evaluation and monitoring of PRP involvement
e	a synthesis of the identified barriers and facilitators to patient involvement, encompassing contextual factors and the strategies used within the included studies

### Supplementary Table 7. Key excerpts on barriers and strategies to enhance PRP involvement.

Concept	Barriers	Excerpts on barriers	Strategies to Enhance Patient Involvement	Excerpts on strategies
<b>Emotional and Personal Factors</b>	<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>	<p><i>“Resources constraints may limit the capability to train and accommodate the needs of the involved patients.” [22]</i></p>	<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>Recognize PRP contributions</li> </ul>	<p><i>“Creating a safe space where patient partners and researchers feel comfortable to collaborate” [41]</i></p> <p><i>“This recognition and appreciation for mutual learning and respect built on the established research partnership, and made reflecting on the challenges more comfortable.”[53]</i></p>
<b>Communication and Relationship</b>	<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>	<p><i>“Lack of genuine engagement feeling may also arise from inadequate patient team diversity and the absence of patient coleadership and power sharing, and not leaving rooms for discussions or allowing time for authentic partnership”. [22]</i></p> <p><i>“The use of medical jargon and the nature of some of the discussion topics such as ethics applications may make it difficult for patients and other stakeholders to understand and follow what is being discussed” [22]</i></p>	<ul style="list-style-type: none"> <li>Appoint a coordinator to facilitate PRP involvement</li> <li>Clarify patient roles and objectives</li> <li>Avoid complex medical terminology</li> <li>Exchange mutual expectations early at project initiation.</li> <li>Ensure open and transparent communication</li> <li>Ensure feedback and trust</li> </ul>	<p><i>“The assigned PC coordinator should take the lead in setting up meetings and ensuring that infrastructures such as video calling technology are accessible to PC members. In addition, the PC coordinator should, at the start of the project, mediate discussions to align expectations from all parties involved.” [2]</i></p> <p><i>“In describing the responsibilities and practical tasks undertaken, values and ethical considerations (eg, mutuality, understanding, respect and diversity) that underpin patient engagement in research are revealed (...)”[53]</i></p>
<b>Training and Support</b>	<ul style="list-style-type: none"> <li>Lack of awareness about PRP involvement among researchers</li> </ul>	<p><i>“Lack of researcher training opportunities to guide meaningful</i></p>	<ul style="list-style-type: none"> <li>Increase awareness about importance of PRP involvement</li> </ul>	<p><i>“(…) importance of providing training and educational resources to support and enhance patient</i></p>

	<ul style="list-style-type: none"> <li>• Overburdening of PRPs</li> <li>• Inadequate training and support of PRP</li> <li>• Lack of resources and compensation of PRP</li> </ul>	<p><i>patient engagement". [41]</i></p> <p><i>"Insufficient researcher resources to support patient partners including time and budget restrictions" [41]</i></p>	<ul style="list-style-type: none"> <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>	<p><i>involvement in research."</i>[26]</p> <p><i>"Three studies reported offering training sessions for researchers to facilitate patient engagement, which included exercises to improve communicating research to non-scientists." [41]</i></p>
<b>Research Process and Pace</b>	<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>	<p><i>"(...) working together in a joint intellectual effort (...) meant delays to the scheduled release of promotional materials, and contributed additional unanticipated hours that had not been bracketed into already busy schedules"[53]</i></p>	<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>	<p><i>"It is desirable to estimate the expected time PRP are required to allocate for the project (e.g., 4 h/month over 6 months), with feasible timelines (e.g., feedback within 2 weeks)."[15]</i></p>
<b>Collaboration and Engagement</b>	<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>	<p><i>"Aside from the challenges of identifying appropriate PRP, research teams may struggle with the lack of awareness of the need and impact of the PRP role, identification of diverse PRP (...)"[21]</i></p>	<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>	<p><i>"Engagement of the patients early in the decision process is critical (...)"[22]</i></p> <p><i>"Whatever the nature of a project, it is essential that the patient voice is represented in early discussions when formulating the concept and idea."[2]</i></p> <p><i>"Goals and expectations should be discussed in the early stages of the project"[27]</i></p>

Supplementary Table 8. Key excerpts on activities and roles of PRPs.

Areas of involvement	Activities and roles of PRPs	Excerpts from the articles
<b>Development/ Design</b>	<ul style="list-style-type: none"> <li>• Guidelines development [22], including voting on draft recommendations [24]</li> <li>• PRO development [5,21]</li> <li>• Grant application [3]</li> <li>• Survey / questionnaire development [2,3]</li> <li>• Interview guide [67]</li> <li>• Tools (educational or others) [3,4,58]</li> <li>• Patient facing materials (develop patient information sheets, pamphlets, glossary, distribution and use of booklet, website, poster) [3,6,43]</li> <li>• Developing or reviewing (recommendations) lay summaries [4,5]</li> </ul>	<p>“...patient engagement must continue if there is a public reason for the topic reconsideration and whether and when the guidelines require updates apart from new evidence.” [22]</p> <p>“The involvement of patients is (...) most tangible in the development of its international management recommendations for rheumatic diseases. According to its standardised operational procedures, involvement of PRPs is pivotal in every phase of the development project.” [5]</p> <p>“PRPs were involved in decisions regarding design of interview and focus group protocols, analysis of transcripts, draft language of items(...). This strategy of patient involvement ensures that PROs are grounded in patient data, have face and content validity and are comprehensive.” [5]</p> <p>“(...) full PRP participation in accordance with the EULAR recommendations has been the development of two patient-derived impacts of disease scores for rheumatoid arthritis and psoriatic arthritis. (elaboration and validation of composite indices)” [5]</p> <p>“Since 2012, EULAR develops public summaries of all its management recommendations that are freely available on their website. These summaries are produced with the active involvement of PRPs who take responsibility for checking relevance, comprehension and completeness. They also assist in reviewing summaries of scientific publications of the Annals of Rheumatology. Finally, three PRPs wrote a lay version of the GRAPPA treatment recommendations for psoriatic arthritis.” [5]</p> <p>“PRPs contributed actively to a number of research activities over the 4 year project, it included:</p> <ul style="list-style-type: none"> <li>• Attending and contributing to annual scientific meetings and regular teleconferences</li> <li>• Development of a glossary resource (WP1–4)</li> <li>• Contributing to a meta-synthesis of qualitative literature on public perceptions of predictive testing [13, 14] (WP4)</li> <li>• Contributing to the development of interview schedules (including question setting) and the interpretation of qualitative data [12, 46] (WP4)</li> <li>• Contributing to the development of informational resources for those at risk (WP4)</li> <li>• Evaluating a web-based platform for the communication of risk information (WP4)</li> <li>• Developing a questionnaire for patients undergoing a lymph node biopsy procedure (WP3)</li> <li>• Developing informational resources for patients about RA such as the ‘Metaphor Project’ (a collaboration between Eva C Johansson (PRP) and Dr. Heidi Wähämaa)</li> <li>• Exploring the communication of scientific concepts via the use of metaphors and visual representations</li> <li>• Contributing to the project website (e.g. providing news items and reports, creating subtitles for videos) (WP4)</li> </ul>

		<ul style="list-style-type: none"> <li>Developing lay summaries of EuroTEAM methods and findings (e.g. lay summary of metabolomics in EuroTEAM) (WP2)</li> <li>Developing posters for dissemination at the European League Against Rheumatism (EULAR) Congress (WP1–4)” [3]</li> </ul>
<b>Leadership</b>	<ul style="list-style-type: none"> <li>Establishing a patient association [5]</li> </ul>	<p>“Creaky Joints, a patient organisation founded by a person with RA, was one of the collaborating partners. (...) Creaky Joints also became a successful applicant of the second project with the objective of developing strong partnerships with trialists to conduct patient-centred comparative effectiveness research.” [5]</p>
<b>Co-leadership role</b>	<ul style="list-style-type: none"> <li>Member of steering committee [7] (eg. EULAR, FOREUM [17], GRAPPA [62])</li> <li>Member of working groups (eg. GRAPPA [8] )</li> </ul>	<p>“Offering advice as a member of a project steering group” [7]</p> <p>“The Glasgow Patient Involvement in Rheumatology Research (PIRR) group is in the early stages of its development with patient representation on clinical trial steering groups” [7]</p> <p>“Within the GRAPPA–Outcome Measures in Rheumatology (OMERACT) Core Set group, 3 PRPs worked on the steering committee, as well as additional PRPs were involved in the working subgroups; particularly in the Physical Function Working Subgroup.” [8]</p>
<b>Coauthorship</b>	<ul style="list-style-type: none"> <li>Writing research papers (co-authoring) [3]</li> <li>Writing research protocol [57]</li> </ul>	<p>“Coauthorship is a recognition of the contributions made by patients, and is the ultimate proof of equal and meaningful partnerships”. [5]</p> <p>“getting involved in (...) writing book chapters and magazine articles; (...) writing conference abstracts, and contributing to academic papers” [54]</p>
<b>Education</b>	<ul style="list-style-type: none"> <li>Trainer at a training program [6]</li> <li>Mentoring less-experienced PRPs [39]</li> </ul>	<p>“one full-day course was conducted by two patient PRPs and some trainings were conducted by a trained lay person and a patient PRP.” [6]</p> <p>“(...) patients and caregivers who have experience being engaged on a study team can effectively serve as mentors for patient families new to the role of research partner who can greatly benefit from their experiences.” [39]</p>
<b>Planning</b>	<ul style="list-style-type: none"> <li>Strategic planning [43,48]</li> <li>Event planning: organize, communicate [53]</li> <li>Interview schedules[3]</li> </ul>	<p>“PRP also created their own governance document and PRP handbook (outlining how the PRP network works within GRAPPA to fulfill expectations and achieve its own goals, including ethical considerations), approved by the GRAPPA executive committee”[21]</p>
<b>Facilitation</b>	<ul style="list-style-type: none"> <li>Session at a conference[54]</li> <li>Held sessions in a meeting [69]</li> </ul>	<p>“...key youth development opportunities taken up by the young people include facilitating a session at a national rheumatology conference, presenting at 9 other conferences (7 national, 2 international)” [54]</p> <p>“(...) co-presenting at conferences” [54]</p>
<b>Reviewer</b>	<ul style="list-style-type: none"> <li>Grant application [2]</li> <li>Research projects (ongoing) [5,59]</li> <li>Summaries of scientific publications [5]</li> </ul>	<p>“Reviewing grant applications is an effective way for patients to influence research agendas. From its inception, the Foundation for Research in Rheumatology involves PRPs in its governing bodies and in the review of research proposals. Members of the Consumer Advisory Group (CAG) of the Australian and New Zealand Musculoskeletal Clinical Trials network operate as PRPs and review all trials from a patient’s perspective. Clinical trialists need to respond to their feedback before they are endorsed by the network.” [5]</p> <p>“They also assist in reviewing summaries of scientific publications of the Annals of Rheumatology.” [5]</p>

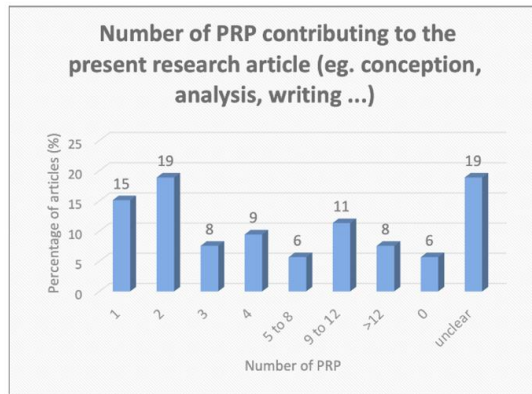


<b>Recruitment</b>	<ul style="list-style-type: none"> <li>• Support recruitment of PRPs (to a project or association). [3] [6] [68]</li> </ul>	<p><i>"The patient partners, along with other patient organisations and charities, recruited nearly half of all participants for the Delphi survey" [68]</i></p> <p><i>"Additional PRPs were recruited via clinician researchers and PRPs' own networks, resulting in a panel of 9 PRPs" [3]</i></p>
<b>Evaluation</b>	<ul style="list-style-type: none"> <li>• Training program [6]</li> </ul>	<p><i>" (...) the trainers (including PRPs) completed an evaluation form containing closed and open questions asking about the conduction of the training course as well as for suggestions regarding the preparation of the trainers in addition to the training itself." [6]</i></p>
<b>Participation</b>	<ul style="list-style-type: none"> <li>• In dissemination of research results [3,7]</li> <li>• Attendance of conferences and scientific meetings [3,41]</li> <li>• In meetings[2], discussions [67]</li> <li>• In quality of care improvement programs [52,61]</li> </ul>	<p><i>"Patient representatives may as well post drafts of evidence summaries and conclusion for the public comments, which may improve guidelines awareness and implementation." [22]</i></p> <p><i>"Within GRAPPA, (...) the patient role has become more formalized, with patients attending the 2013 annual meeting and each subsequent annual meeting as PRP." [21]</i></p> <p><i>"...involved as patient-partners in peer-reviewed research and quality of care improvement programs." [52]</i></p>

GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; PRO: Patient Reported Outcomes.

## Supplementary Figure 1. Number of PRPs contributing or participating in the study.

### A. Number of PRPs stated as coauthors



### B. Number of PRPs contributing to the research project

