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Miscellaneous

Building the future of patient-centred research: an EULAR PARE community of practice advancing patient research partner involvement in rheumatology

Maarten de Wit[1,2,*], Martin Stevens[2], Krystel Aouad[3], Peter Boyd[4], Nele Caeyers[5,6], Loreto Carmona[7], Kristina Chingov[8], Diederik De Cock[9], Mrinalini Dey[10], Christopher J. Edwards[11], Muriel Elhai[12], Laure Gossec[13,14], Ingrid de Groot[15], Souzi Makri[16,17], Patricia Pennings[18], Jette Primdahl[19,20], Diana Rodrigues[8], Simon R. Stones[21,22,23,24], Paul Studenic[25], Bente Appel Esbensen[26,27]

[1] *The European Alliance of Associations for Rheumatology (EULAR) People with Arthritis and Rheumatism in Europe (PARE) Patient Research Partner, Zaltbommel, The Netherlands*
[2] *Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, Leeds, UK*
[3] *Saint George Hospital University Medical Center, Saint George University of Beirut, Beirut, Lebanon*
[4] *EULAR PARE past chair, Dublin, Ireland*
[5] *EULAR PARE Patient Research Partner, Mol, Belgium*
[6] *ReumaNet vzw., Brussels, Belgium*
[7] *Instituto de Salud Musculoesquelética, Madrid, Spain*
[8] *EULAR, Zürich, Switzerland*
[9] *Research Centre for Digital Medicine (REDM) Research Group, Department of Public Health, Vrije Universiteit Brussel, Brussels, Belgium*
[10] *Centre for Rheumatic Diseases, Faculty of Life Sciences and Medicine, King's College London, London, UK*
[11] *National Institute for Health and Care research (NIHR), Southampton Clinical Research Facility, University Hospital Southampton, Southampton, UK*
[12] *University Hospital Zürich, University of Zürich, Zürich, Switzerland*
[13] *Sorbonne Université, National Institute of Health and Medical Research (INSERM), Institut Pierre Louis d'Epidémiologie et de Santé Publique, Team Pepites, Paris, France*
[14] *Assistance Publique – Hôpitaux de Paris (AP-HP), Pitié-Salpêtrière Hospital, Rheumatology Department, Paris, France*
[15] *EULAR PARE Patient Research Partner, Rotterdam, The Netherlands*
[16] *EULAR PARE Patient Research Partner, Cyprus*
[17] *EULAR Vice-President, Zürich, Switzerland*
[18] *National Association ReumaZorg Nederland, Nijmegen, The Netherlands*
[19] *The Danish Center for Expertise in Rheumatology, Danish Hospital for Rheumatic Diseases, University Hospital of Southern Denmark, Sønderborg, Denmark*
[20] *Department of Regional Health Research, University of Southern Denmark, Odense, Denmark*
[21] *EULAR PARE Patient Research Partner, Manchester, UK*
[22] *Saol & Stones, Manchester, UK*
[23] *Amica Scientific, Macclesfield, UK*
[24] *University of Salford, Salford, UK*
[25] *Internal Medicine 3, Division of Rheumatology, Medical University Vienna, Vienna, Austria*

*Correspondence to Dr. Maarten de Wit, EULAR PARE Patient Research Partner, Zaltbommel, The Netherlands.
E-mail address: Martinusdewit@hotmail.com (M. de Wit).
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[26] *Copenhagen Center for Arthritis Research (COPECARE), Center of Rheumatology and Spine Disorders, Centre of Head and Orthopaedics, Copenhagen University Hospital – Rigshospitalet, Copenhagen, Denmark*
[27] *Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark*

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ABSTRACT

Objectives: The European Alliance of Associations for Rheumatology (EULAR) supports patient involvement in research through its People with Arthritis and Rheumatism in Europe (PARE) network. Updated 2023 recommendations promote inclusion of Patient Research Partners (PRPs) in research; however, implementation remains inconsistent. Key challenges include unclear PRP roles, limited researcher preparedness, insufficient support, and a lack of systematic feedback on impact. We describe how the EULAR PARE community of practice used cocreation to develop practical, implementation-focused solutions.

Methods: The 2024 EULAR PARE conference used a World Café format to explore stakeholder experiences and identify barriers to collaborative research. Building on these findings, the 2025 conference centred on 4 multistakeholder Hackathon workshops to codevelop solutions. Participant experience in 2025 was evaluated using the Patient Engagement In Research Scale (PEIRS-22).

Results: The 2024 conference identified 4 priority challenges: unclear PRP roles, variation in uptake across Europe, limited researcher training, and uncertainty about PRP impact due to insufficient feedback. In 2025, Hackathons generated actionable outputs, including concepts for a PRP toolkit and role descriptions, profiles for national PRP coordinators and ambassadors, a Supporting Patient Research Collaboration hub, a draft researcher training course, and a framework for evaluating PRP involvement. Fifty-four participants (46% response rate) completed PEIRS-22; the mean score was 88, indicating high, meaningful engagement.

Conclusions: From 2024 to 2025, the EULAR PARE community identified key challenges and translated them through Hackathon workshops into feasible solutions to strengthen collaborative research. The ongoing next steps will be to refine, pilot, and scale these solutions across Europe.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- European Alliance of Associations for Rheumatology (EULAR) developed recommendations for involving Patient Research Partners (PRPs) in research, updated in 2023.
- Uptake of PRP recommendations across Europe remains inconsistent, with challenges in role clarity, support structures, and researcher preparedness.
- Evaluation of PRP contribution and feedback from researchers is often limited, increasing the risk of tokenistic involvement.

WHAT THIS STUDY ADDS

- The 2024 EULAR People with Arthritis and Rheumatism in Europe (PARE) conference identified key challenges that were turned into feasible solutions (tools, roles, training, evaluation) through Hackathon workshops at the 2025 EULAR PARE conference.
- Using time-bound Hackathons as part of a wider strategy of long-term cocreation resulted in high scores of perceived meaningful engagements at the 2025 EULAR PARE conference.
- The EULAR-funded Implementing New Strategies for PRP Involvement in Research at EULAR project provides a platform to implement and scale these cocreated solutions while strengthening the EULAR PARE community of practice in collaborative research.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- These findings support more consistent PRP involvement through clearer roles, structured support, and targeted researcher training.
- The next steps will promote implementation of EULAR recommendations for PRP involvement across Europe.
- Implementation of routine monitoring and evaluation of both impact and process quality will enhance PRP involvement in rheumatology research.

INTRODUCTION

Over the last 2 decades, the European Alliance of Associations for Rheumatology (EULAR) has built a distinctive model of collaboration between academia, healthcare professionals, and the patient community. Involvement of patients and caregivers is embedded within EULAR's vision, strategy, and organisational culture [1] through the People with Arthritis and Rheumatism in Europe (PARE) pillar [2], ensuring that the perspectives of people living with rheumatic and musculoskeletal diseases (RMDs) are integrated across all activities, including research, education, and advocacy. People with RMDs are represented at all organisational levels within EULAR, actively contributing to all task forces developing recommendations, and have equal voting rights alongside other members.

Comparable patient involvement initiatives exist in Europe, particularly through patient organisations, European Union–funded research consortia, and patient engagement platforms [3]. However, EULAR appears distinctive among European medical speciality societies in the extent to which people with RMDs are structurally embedded through PARE and the Patient Research Partner (PRP) network, supported by dedicated training, recommendations, and routine involvement in scientific projects [4]. EULAR PARE brings together a network of national patient organisations and supports the involvement of people with lived experience of RMDs. Through PARE, EULAR

facilitates a wide range of patient-centred activities, including a dedicated programme at the annual EULAR Congress, an annual patient-led EULAR PARE conference, and initiatives such as the essay competition Edgar Stene Prize and the knowledge transfer programme. PARE also plays a central role in advocacy, awareness-raising (eg, World Arthritis Day) and capacity-building efforts, strengthening patient organisations and contributing to policy discussions at the European level.

In 2009, EULAR approved a PARE proposal to develop recommendations for collaboration with patient representatives in scientific research [5]. The recommendations published in 2011 led to the establishment of a network of trained PRPs [6], followed by the appointment of a dedicated staff member in EULAR to support the network. With the growing demand for involvement of patient representatives in research, the need for education of PRPs has also increased. In 2017, PARE initiated an EULAR study group for collaborative research [7], and in 2019, PARE started the development of a comprehensive e-learning course for PRPs as part of EULAR's educational offering [8]. Reflections on good examples of patient involvement in research became more important with the arrival of international research consortia in which EULAR actively participates [9]. A chronological overview of EULAR activities to support the network of PRPs is shown in Table 1. In this context, and in conjunction with the publication of the updated EULAR PRP recommendations [10], the PARE leadership decided to focus 2 EULAR PARE conferences in November 2024 and November 2025 on the challenges surrounding collaborative research.

The primary aim of this article is to provide a practice-based perspective on PRP involvement in rheumatology research, focusing on how challenges identified at the 2024 conference [11] were translated into cocreated solutions at the 2025 conference [12]. In addition, the article describes the use of a Hackathon approach during the 2025 conference as an example of cocreation methodology to support PRP involvement in rheumatology research.

Table 1
Chronological overview of EULAR activities to support the network of PRPs

2009	Approval for the development of recommendations for the inclusion of patient representatives in scientific projects
2010	Publication of the EULAR recommendations for patient−researcher collaboration
	First EULAR training for PRPs, Brussels (n = 18)
2011	Establishment of the EULAR network of PRPs
2012	First PRP Network meeting, Berlin (n = 14)
2013	Brochure 'Patient involvement in research. A way to success', and the first set of 8 reference cards was published
	Second EULAR Training for PRPs, Brussels (n = 18)
2014	Appointment of dedicated PRP coordinator
	PRP involvement in the development of lay summaries of EULAR management recommendations
2015	Second PRP Network meeting, Amsterdam (October) (n = 31)
	Start PRP involvement in the assessment of FOREUM grant applications from a patient perspective and as members of the scientific committee
2016	Establishment of the PARE PRP working group
	First PRP coordinators meeting, London (June) (n = 16)
2017	Establishment of the EULAR Study Group for Collaborative Research
	EULAR PRP involvement in EMA committees and in European IMI-funded research consortium (HarmonicSS)
	Third PRP Network meeting, Amsterdam (n = 45)
	Launch of the virtual PRP newsletter
2019	Approval of development of an online training course for PRPs
	Fourth PRP Network meeting, Prague (n = 50)
2020	EULAR PRP Network strategy for 2020-2025—support national PRP networks
2021	EULAR research committee includes 3 PRPs
2022	Launch of 1st EULAR online PRP course (n = 47) in conjunction with the EULAR PRP glossary and the new PRP reference cards
	First Meeting for national PRP coordinators
2023	Introduction of PRP bursaries for the EULAR Congress
2024	Publication of the updated EULAR recommendations for patient−researcher collaboration
	PRP involvement main topic of the PARE conferences in 2024 and 2025 (Brussels)
2025	Approval EULAR-funded implementation project INSPIRE
2026	Recruitment of national PRP ambassadors

EMA, European Medicine Agency; EULAR, European Alliance of Associations for Rheumatology; FOREUM, Foundation for Research in Rheumatology; INSPIRE, Implementing New Strategies for PRP Involvement in Research at EULAR; PARE, People with Arthritis and Rheumatism in Europe; PRP, Patient Research Partner.

2024 and 2025 EULAR PARE conferences

The EULAR PARE conference is an annual patient-led meeting dedicated to a specific theme, featuring keynote speakers, debates, a best practice fair, and workshops over 3 days, with preconference sessions focused on volunteer training and targeted group meetings. What started in 1998 as a single-pharma-sponsored event called 'Arthritis Patients On the Move' (APOM) became, 10 years later, a fully EULAR-facilitated PARE conference. Nowadays, the conference is organised by a dedicated core group, comprising PARE leadership (Chair, Chair-Elect/Past Chair, and Vice-President PARE), subject matter experts with specific interests in the conference topic, and EULAR PARE staff members. The 2024 and 2025 conferences were held in Brussels, Belgium, and each attracted over 120 participants, including PRPs and other patient representatives (including young people, parents, and carers), researchers, rheumatologists, health professionals in rheumatology (HPR), the Emerging EULAR Network (EMEUNET), and other stakeholders (Table 2).

The 2024 conference featured a 3-hour World Café format [13,14], during which participants engaged in small-group

Table 2
Stakeholder groups represented at the EULAR PARE conference in 2024 and 2025

Participants	PARE conference 2024	PARE conference 2025
EULAR PARE internal stakeholders		
EULAR and PARE leadership members (board, council, and committee members)	27	33
National PARE member representatives	66	55
EMEUNET members	4	8
YoungPARE	7	9
Patient research partners	65	61
Researchers	13	26
EULAR staff members	8	8
EULAR PARE external stakeholders		
Researchers	3	5
EMA, EU representatives	1	0
Personal assistants	9	14
Others	1	0

EMA, European Medicine Agency; EMEUNET, Emerging EULAR Network; EU, European Union; EULAR, European Alliance of Associations for Rheumatology; PARE, People with Arthritis and Rheumatism in Europe.
Some conference participants belong to >1 stakeholder group and have been counted multiple times.

Table 3
Hackathon workshops: an example of cocreation

Team	Activities
Members of the PARE leadership or conference core group	Designed broad topic headings and gave examples of possible outputs; introduced the Hackathon concept.
Hackathon workshop team members	Developed topics and designed Hackathon sessions to address questions.
Conference delegates	Added wide-ranging experience and knowledge in Hackathon sessions to create concrete outcomes and deliverables.
Ongoing development via the INSPIRE project[a]	Further development of Hackathon topics, possible grant applications, etc.

EULAR, European Alliance of Associations for Rheumatology; INSPIRE, Implementing New Strategies for PRP Involvement in Research at EULAR; PARE, People with Arthritis and Rheumatism in Europe; PRP, Patient Research Partner.
[a] INSPIRE project is a EULAR-funded project focusing on implementation of EULAR recommendations for the involvement of patient research partners in rheumatology research: 2023 update [10].

discussions on 12 tables across 3 rounds to explore experiences and perspectives on collaborative research. This format ensured broad engagement and facilitated the development of shared understanding and language [15]. Although several examples of good practice were identified, 4 key challenges emerged [11]:

1. Lack of clear role descriptions for PRPs, leading to misaligned expectations between PRPs and researchers and limited access to guidance and support.
2. Variation across Europe in the acceptance and implementation of collaborative research.
3. Limited training opportunities for researchers to collaborate effectively with PRPs.
4. Uncertainty among PRPs regarding their added value, compounded by insufficient feedback and a lack of structured evaluation mechanisms.

The 2025 conference was designed to build on these findings through a cocreation approach involving representatives from all EULAR communities (Table 3). The primary objective of this conference was to develop solutions to the challenges identified in 2024 [11]. To support this, the programme included 4 Hackathon workshops focused on implementation-oriented collaboration [16]. The Hackathon topics were decided by the PARE conference core group before the conference, with each Hackathon assigned to workshop teams of 5 to 8 people, including PRPs, researchers, rheumatologists/HPRs, and dedicated EULAR staff members. The teams held several preparatory online meetings and formulated objectives and deliverables for their Hackathons, aligned to the overall aims of the 2025 conference (Fig 1).

Conference participants were invited to indicate their preferred Hackathon topic and were subsequently allocated across the 4 groups. Each Hackathon workshop was supported by a preparatory online meeting before the conference to introduce team members to each other and outline objectives. Preconference materials were made available via the virtual PARE conference platform, supporting participants in familiarising themselves with the workshop topics and establishing a shared understanding across groups, thereby facilitating informed and productive discussions during the Hackathons.

During the Hackathons, all participants contributed to different parts of the creation of content and organised their own working procedures, division of tasks, and reporting of progress and outcomes. Time limitations prevented some workshops from achieving all their objectives, but allowed them to present consensus on their ideas and practical next steps. The *I*mplementing *N*ew *S*trategies for *P*RP *I*nvolvement in *R*esearch at *E*ULAR (INSPIRE) project ensures that these ideas will be taken forward for concrete implementation.

Cocreation through Hackathon workshops

An additional objective of the 2025 conference was to familiarise participants with the principles of cocreation and provide first-hand

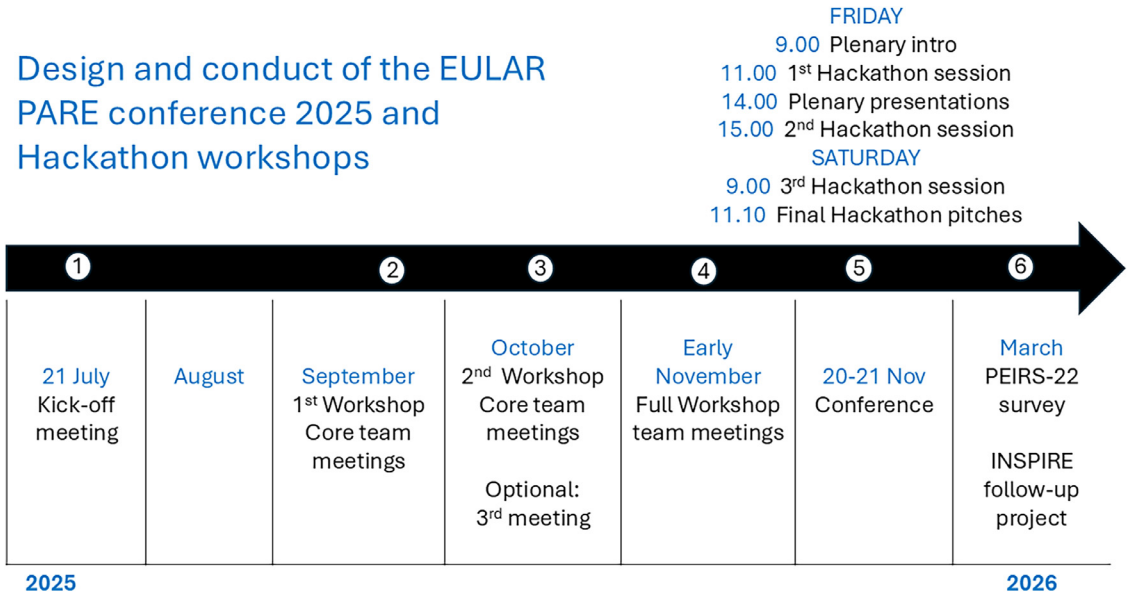

Figure 1. Flow chart 2025 EULAR PARE conference program development. EULAR, European Alliance of Associations for Rheumatology; PARE, People with Arthritis and Rheumatism in Europe; PEIRS-22, Patient Engagement In Research Scale.

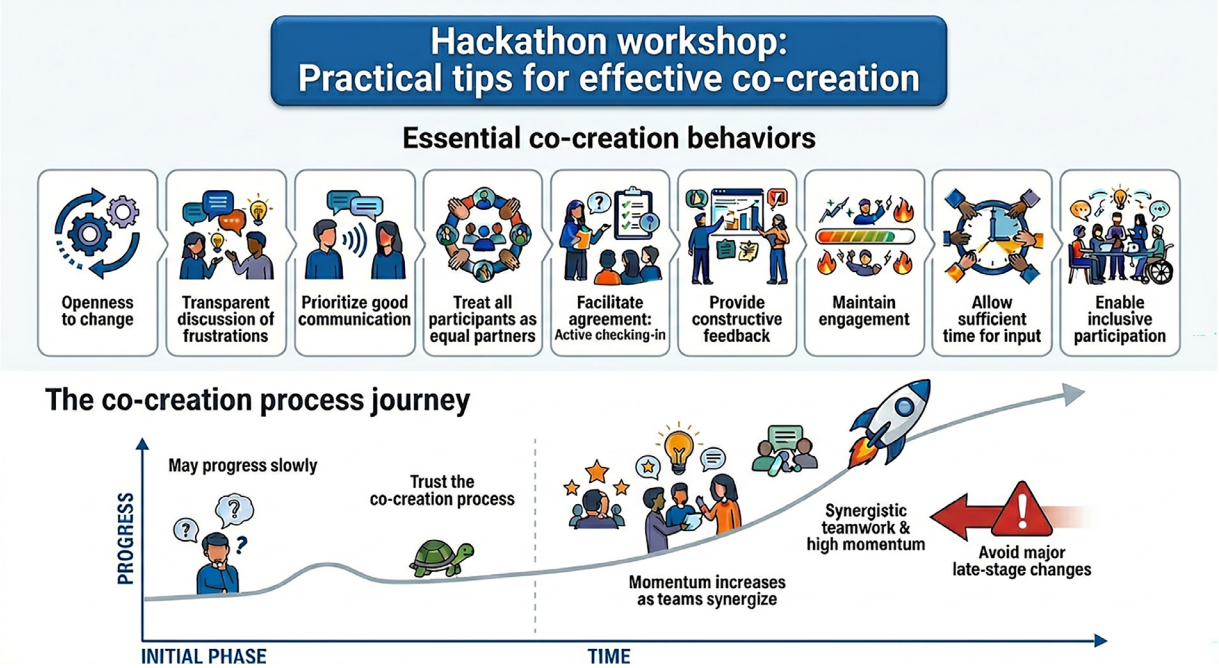

Figure 2. Hackathon workshop: practical tips for effective co-creation. 'Figure 2 includes influences from Knowles [19], Coproduction collective [18], Laidlaw [21], and Stevens [26].'

experience of its application through the Hackathon workshops. In the EULAR PARE strategy, cocreation is defined as *'a hands-on collaborative approach where delegates from all pillars of EULAR share ideas, shape content and make decisions collectively to achieve concrete outcomes/deliverables'* [2]. Although cocreation is often used interchangeably with terms such as codesign and coproduction, participants were encouraged to focus on the broader values and characteristics underpinning cocreation rather than adhering to rigid definitions. Drawing on selected literature [17–21], cocreation can be understood as a set of guiding principles rather than a strictly defined methodology. Key characteristics include the importance of relationship-building and the recognition that both the collaborative process and its outputs are equally valuable. Authenticity is central, particularly the need to avoid tokenistic involvement of PRPs.

Equally important is the ability to acknowledge and constructively manage disagreement within cocreation spaces. Such 'productive tensions' can be understood as constructive frictions between different forms of knowledge and perspectives [19]. Rather than being resolved, these tensions may act as supportive and generative forces within collaborative research processes [22,23], enabling participants to discuss differences and adapt collectively [19].

A Hackathon is an innovative, time-bound method that provides a structured framework for collaborative problem-solving and the development of practical solutions [16]. It aligns closely with cocreation principles by fostering equitable, multistakeholder collaboration towards clearly defined and tangible outcomes [24,25]. Hackathons rely on intense teamwork, drawing on diverse expertise, knowledge, and networks (including online resources), and emphasise implementation to ensure that outputs are feasible, actionable, and transferable beyond the event itself.

During the keynote lecture at the 2025 conference, Martin Stevens provided practical tips for effective cocreation during the Hackathon workshops, depicted in Figure 2. They include openness to change, transparent discussion of challenges and frustrations, and the use of active 'check-ins' to support alignment. Although cocreation processes may initially progress slowly, momentum typically increases as teams begin to work synergistically and develop trust, reducing the need for major adjustments at later stages.

Hackathon workshop 1: developing resources for PRPs and researchers

Participants at the 2024 conference identified an implementation gap between EULAR PRP recommendation #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*) and #5 (*the research team must provide a supportive environment and facilitate the contribution of PRPs to research*) [10] and current research practice. PRPs often lack access to clear, consolidated information regarding their roles, expectations, and available support. Although EULAR has developed a range of resources, including a PRP glossary, reference cards and comprehensive e-learning courses, these are often fragmented across platforms and difficult to access. In addition, language barriers across Europe limit involvement, and PRPs may feel uncertain about asking questions or contributing actively [27,28].

In response, Hackathon workshop 1 aimed to develop a practical toolkit for both experienced PRPs and other people with RMDs considering involvement in research. The toolkit is designed from a PRP perspective and prioritised clarity,

Table 4
Topics prioritised to include in the toolkit

• Meaningful participation[a]
• The role of a PRP[a]
• Communication in research
• Peer support
• How research projects work
• How to get involved
• What to do when things go wrong[a]
• A set of key questions PRPs can ask researchers

PRP, Patient Research Partner.
[a] Topics voted at the plenary session to prioritise for development during the conference.

accessibility, and engagement. A short preworkshop survey informed the prioritisation of key topics for inclusion in the toolkit (Table 4), which were further refined during the workshop.

Outputs included an infographic illustrating the diversity of PRP roles and contributions (Supplementary File S1), alongside a framework for describing these roles in more detail. Proposed elements include standardised operational procedures (SOPs), a code of conduct, role descriptions, guidance on aligning expectations, and frequently asked questions. The topic '*What to do when things go wrong*' was explored through a narrative video format supported by a matrix of common challenges and potential solutions. Meaningful patient involvement in research was structured into 5 practical areas: communicating research objectives in accessible language, agreeing on timelines and deliverables, defining roles clearly, providing timely feedback, and recognising PRP contributions.

Hackathon workshop 2: enhancing collaboration between national PRP ambassadors/networks and the EULAR PRP network

Across Europe, countries are at different stages of patient involvement in rheumatology research. Some countries have well-established national PRP networks connected to EULAR, whereas others are at an early stage of development or are without formal structures [29]. This variation highlights the need for stronger collaboration between existing and emerging national PRP networks and the EULAR PRP network.

Aligned with EULAR PRP recommendation #6 (*A designated coordinator should support the collaboration of researchers and PRPs*), Hackathon workshop 2 developed role profiles for national PRP coordinators (in countries with an established PRP network) and PRP ambassadors (in countries without a PRP network), outlining key tasks, skills, and competencies. The group also proposed the hypothetical EULAR Supporting PAtient Research Collaboration (SPARC) support hub (Supplementary File S2), designed as a practical resource platform.

This SPARC concept includes 2 complementary components: one supporting emerging networks by providing guidance, training opportunities, templates, and key messaging on the added value of PRPs ('sparking the flames'), and another supporting established networks (including PRP coordinators) through knowledge exchange and collaboration ('keeping the fire going'). In addition, the group recommended updating and improving the accessibility of the PARE guide for establishing national PRP networks [30].

Hackathon workshop 3: developing an educational course for researchers on collaborative research

The increasing requirement for patient involvement in research funding applications has accelerated collaboration between researchers and PRPs. However, findings from the EULAR-funded Implementing Patient Research Partner Engagement in Research (iPRePaRe) study [26], presented at the 2024 PARE conference, highlighted a clear need for training researchers to collaborate effectively with PRPs, a need recognised by both PRPs and researchers. Notably, 63% of surveyed researchers (n = 59) reported having received no prior training in this area.

In line with EULAR PRP recommendation #7 (*Researchers should have access to training and support, to achieve effective communication and collaboration with PRPs as equal partners*) and #8 (*PRPs should have access to training relevant to their roles*) [10], the Hackathon workshop 3 focused on the development of an educational course for researchers. A key challenge identified was designing content and using formats that are attractive, relevant, and feasible (time constraints) for a diverse audience of RMD professionals with varying professional backgrounds and different levels of experience in collaborative research.

Table 5
Potential modules of the educational course for researchers

1. Introduction
2. Assessment of baseline knowledge
3. Why involve PRPs in research?
4. Working together: best and bad practices
5. Matchmaking between PRPs and research projects
6. Communication: speaking the same language
7. Evaluation of knowledge and learning outcomes

PRP, Patient Research Partner.

The proposed course includes core topics such as the rationale for collaboration, matchmaking between researchers and PRPs, communication, expectation management, and examples of best practice (Table 5). It is intended for a broad audience to encourage widespread uptake, including researchers at different career stages, students, and pharmaceutical industry representatives.

A blended learning approach was recommended, combining traditional materials (eg, text-based content) with digital formats, such as videos, infographics, and slides. Participants emphasised the importance of ongoing support beyond course completion, leading to the proposal of a chatbot-based tool ('facilitAIt') to provide tailored feedback on PRP involvement strategies. Flexibility and adaptability were identified as key principles, with modular pathways for different levels of experience and research contexts (eg, mandatory and optional modules, beginner and advanced tracks, content tailored to basic, translational, and clinical research contexts).

Hackathon workshop 4: monitoring and evaluating PRP involvement

The iPRePaRe study also identified discrepancies between PRP and researcher perceptions of collaboration quality [26], partly linked to a lack of structured feedback. This has been consistently identified as a barrier to meaningful collaboration and may reduce motivation among PRPs for continued involvement [31,32].

In response, EULAR introduced recommendation #9, stating that '*Researchers and PRPs should regularly evaluate their collaboration and adjust their way of working when needed*' [10]. However, implementation remains challenging due to the absence of standardised, validated tools and procedures.

Hackathon workshop 4 aimed to address this gap by reviewing existing tools and developing a set of quality indicators for the implementation of the EULAR PRP recommendations, including a structured evaluation process. The group discussed and defined guiding principles (Supplementary File S3) and proposed a monitoring and evaluation process based on the Plan−Do−Study−Act cycle [33] (Supplementary File S4). This approach supports continuous improvement by ensuring that PRP involvement is planned, implemented, evaluated, and adapted iteratively.

Evaluation of the 2025 EULAR PARE conference

In line with the same recommendation #9, the conference organisers evaluated participant experiences using the validated

Table 6
Results from Patient Engagement in Research Scale (PEIRS-22) survey

Respondent role	Number	PEIRS-score mean (SD)[a]
Member of the PARE leadership or conference core group	N = 10	87 (13.3)
Hackathon workshop team members	N = 11	92 (9.4)
Conference delegate	N = 33	87 (9.5)
Total	N = 54	88 (10.2)

PARE, People with Arthritis and Rheumatism in Europe.
[a] Higher scores indicating a higher level of meaningful engagement.

Patient Engagement In Research Scale (PEIRS-22) [34]. This instrument assesses 22 items covering 8 dimensions of meaningful involvement using a 5-point Likert scale from 'strongly disagree' to 'strongly agree'. PEIRS-22 has been previously used to evaluate patient and researcher experiences in several RMD studies [26,35,36]. Benchmarking thresholds for meaningful participation scores, as calculated by the PEIRS-22 developers, are 73 (from not to moderately meaningful), 84 (very meaningful), and 94 (extremely meaningful) [37]. PARE conference respondents provided informed consent to use their data for this publication when they filled in the anonymous PEIRS-22 questionnaire sent 3 months after the PARE conference (February 2026).

A total of 54 participants of 118 (response rate 46%) completed the PEIRS-22 questionnaire, including conference delegates (n = 33), Hackathon workshop team members (n = 11), and members of the PARE leadership or conference core group (n = 10). The overall PEIRS-22 score was 88 (Table 6), indicating a high level of perceived meaningful engagement across all groups. Although participants involved from earlier stages were expected to report higher satisfaction, scores were consistently high across groups. These findings suggest that the conference format, including preparatory activities and Hackathon workshops, may support meaningful cocreation.

INSPIRE project

In 2025, EULAR funded an implementation project called 'INSPIRE'.

INSPIRE provides a unique opportunity to advance the implementation of the updated EULAR PRP recommendations across Europe and beyond, building directly on the workshop outcomes and implementation plans presented at the 2025 EULAR PARE conference. The steering group includes an implementation methodologist and a research fellow and follows the EULAR SOPs for implementation research [38]. The group meets monthly and will, in accordance with recent implementation principles [39], define internal and external stakeholders, conduct contextual analyses, identify barriers and facilitators, develop implementation strategies, and formulate quality indicators. The project is structured as a 3-year implementation taskforce (2026-2028) and is organised into 4 interconnected work packages aligned with the Hackathon themes from the PARE conference (Table 7). The project aims to translate the conference outputs into sustainable implementation strategies, supporting the uptake of updated EULAR PRP recommendations across the life course for different audiences. The wider EULAR PARE community, together with HPRs and researchers, will play a central role in this process.

DISCUSSION

By bringing together all pillars and communities of EULAR across 2 PARE conferences, and supported by sustained leadership commitment, a community of practice (CoP) for cocreation and collaborative research has emerged. This community is characterised by a shared commitment to enhancing opportunities for people with RMDs to influence and improve research and health policy. A broad representation of EULAR engaged at the 2024 and 2025 PARE conferences with a common purpose —to learn from one another and to exchange good and bad practices in collaborative research.

For many participants, the conferences provide not only a platform for learning but also a sense of identity and shared goals. This sense of belonging has become a key factor sustaining the PARE community [40]. An inclusive conference design, grounded in cocreation principles, can reduce barriers and power imbalances, foster equity, and strengthen community building [41]. The resulting CoP extends beyond a professional network, evolving into a social community in which long-term relationships and, in many cases, friendships are formed. This is reflected in initiatives such as the EMEUNET meet PARE

Table 7
Comparison of topics across the PARE Conference 2025 Hackathons and INSPIRE project[a]

Topic	PARE conference 2025	INSPIRE project
Tools for PRPs	Hackathon workshop 1 Development of a PRP role description and a toolkit of resources for PRPs	Work package 1 Dissemination of the EULAR PRP recommendations
Promoting the establishment of PRP networks	Hackathon workshop 2 Support for existing and emerging national PRP networks	Work package 1 PRP Ambassador Network Researcher Ambassador Network Work package 4 Pilot dissemination and implementation projects in 2 countries
Education of researchers	Hackathon workshop 3 Training course for researchers on collaborative research	Work package 3 Development training programme for researchers
Monitoring and evaluation of PRP involvement	Hackathon workshop 4 Strategy for monitoring and evaluating PRP involvement in RMD research	Work package 2 Developing quality indicators for PRP involvement and mapping implementation across Europe

EULAR, European Alliance of Associations for Rheumatology; INSPIRE, Implementing New Strategies for PRP Involvement in Research at EULAR; PARE, People with Arthritis and Rheumatism in Europe; PRP, Patient Research Partner; RMD, rheumatic and musculoskeletal disease.
[a] INSPIRE project is an EULAR-funded project focusing on implementation of EULAR recommendations for the involvement of patient research partners in rheumatology research: 2023 update [10].

sessions at the EULAR Congress [42] and the meetings of the EULAR PARE study group for collaborative research.

Over time, and facilitated by EULAR, this has led to the development of a shared repertoire of resources, experiences, tools, and language that both supports participants and strengthens the integration of the patient voice in research and beyond. Learning within this community is embedded in practice, emerging through collaboration, shared experiences, and ongoing reflection. At the PARE conferences, and particularly within the Hackathon workshops, knowledge was codeveloped as participants engaged in real-world problem-solving.

This article illustrates the value of cocreation, operationalised through Hackathons, to bring together diverse stakeholders and generate practical, implementation-oriented solutions to preidentified challenges. The outputs presented include proposals for a centralised repository of resources for collaborative research, the development of a network of PRP ambassadors to support countries with less established practices, and the creation of a virtual support hub to strengthen collaboration between national and EULAR-level PRP networks. The guide for the establishment of new PRP networks will be revised, and its accessibility improved. Experience from initiatives such as the patient-led virtual PxP conference ('For patients, by patients') further supports the value of accessible, shared resource platforms for patient involvement [43].

The findings also highlight the need to strengthen researchers' preparedness for effective collaboration with PRPs, an unmet need widely recognised in the literature [44,45]. In addition, the lack of standardised approaches to monitoring and evaluating PRP involvement remains a key challenge. The work undertaken during the PARE conference represents an essential first step towards addressing this gap, through the development of quality indicators and a structured evaluation approach aligned with EULAR recommendations.

Evaluation of PARE conference participants' experiences using the PEIRS-22 instrument indicated a high level of perceived meaningful engagement across groups. Despite the moderate response rate (46%), the findings suggest that the hackathon conference design and cocreation approach may support meaningful patient involvement in rheumatology research.

Through the INSPIRE project, EULAR aims to ensure that the outputs of the 2 PARE conferences extend beyond conceptual discussions and are translated into practical tools, guidance, and processes that can be implemented across diverse contexts. By providing a structured framework for continuity, INSPIRE represents an important step towards embedding sustainable, meaningful patient involvement in rheumatology research and strengthening research cultures within and beyond EULAR.

CRediT authorship contribution statement

Maarten de Wit: Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Conceptualization. **Martin Stevens:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Krystel Aouad:** Writing – review & editing, Formal analysis, Conceptualization. **Peter Boyd:** Writing – review & editing, Formal analysis, Conceptualization. **Nele Caeyers:** Writing – review & editing, Formal analysis, Conceptualization. **Loreto Carmona:** Writing – review & editing, Formal analysis, Conceptualization. **Kristina Chingov:** Writing – review & editing, Visualization, Formal analysis, Conceptualization. **Diederik De Cock:** Writing – review & editing, Software, Formal analysis, Conceptualization. **Mrinalini Dey:** Writing – review & editing, Formal analysis, Conceptualization. **Christopher J. Edwards:** Writing – review & editing, Formal analysis, Conceptualization. **Muriel Elhai:** Writing – review & editing, Formal analysis, Conceptualization. **Laure Gossec:** Writing – review & editing, Formal analysis, Conceptualization. **Ingrid de Groot:** Writing – review & editing, Formal analysis, Conceptualization. **Souzi Makri:** Writing – review & editing, Formal analysis, Conceptualization. **Patricia Pennings:** Writing – review & editing, Formal analysis, Conceptualization. **Jette Primdahl:** Writing – review & editing, Formal analysis, Conceptualization. **Diana Rodrigues:** Writing – review & editing, Formal analysis, Conceptualization. **Simon R. Stones:** Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization. **Paul Studenic:** Writing – review & editing, Formal analysis, Conceptualization. **Bente Appel Esbensen:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization.

Competing interests

SRS is an employee of Amica Scientific, holds an honorary academic research appointment at the University of Salford, has received honoraria from National Institute for Health and Care Research (NIHR), Sage, Taylor & Francis, BMJ, The Kennedy Trust, University of Leeds, and University of British Columbia, is a Board Director of RAiISE, a charitable incorporated organisation registered in England and Wales Number 1180704, and Committee member of the International Society for Medical Publication Professionals Patient Engagement Task Force, European Alliance of Associations for Rheumatology (EULAR) People with Arthritis/Rheumatism in Europe (PARE) Committee, EULAR Congress Committee, EULAR Council, and PxP 2025 Organising Committee. KC and DR are employees of EULAR. All other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this publication.

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Patient consent for publication

The European Alliance of Associations for Rheumatology (EULAR) People with Arthritis and Rheumatism in Europe (PARE) conference is organised by and with people with RMDs. In accordance with EULAR recommendations, PRPs and several national and EULAR PRP coordinators were involved in the

design and conduct of this conference. Five EULAR PARE PRPs (NC, IdG, SM, SS, and MdW) and 2 patient representatives (PB, PP) are coauthors of this publication. The study findings are reported according to the Guidance for Reporting Patient and Public Involvement in research (GRIPP2) [46], including a populated short form (Supplementary File S5).

Ethics approval

Not applicable.

Provenance and peer review

Not commissioned; externally peer reviewed.

Declaration of generative AI and AI-assisted technologies in the writing process

Figure 2 is generated with Google Gemini. Supplementary Files S1 and S2 are generated with MS Co-pilot. Supplementary Files S3 and S4 are generated with Canva.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.ero.2026.100220.

Orcid

Maarten de Wit: http://orcid.org/0000-0002-8428-6354
Martin Stevens: http://orcid.org/0000-0002-6142-5278
Krystel Aouad: http://orcid.org/0000-0001-8708-9324
Loreto Carmona: http://orcid.org/0000-0002-4401-2551
Diederik De Cock: http://orcid.org/0000-0002-5656-6236
Mrinalini Dey: http://orcid.org/0000-0001-6858-4338
Christopher J. Edwards: http://orcid.org/0000-0002-8233-6602
Muriel Elhai: http://orcid.org/0000-0001-8627-5758
Laure Gossec: http://orcid.org/0000-0002-4528-310X
Ingrid de Groot: http://orcid.org/0000-0001-8436-8977
Souzi Makri: http://orcid.org/0000-0001-7285-7124
Jette Primdahl: http://orcid.org/0000-0002-1049-4150
Simon R. Stones: http://orcid.org/0000-0002-5943-1310
Paul Studenic: http://orcid.org/0000-0002-8895-6941
Bente Appel Esbensen: http://orcid.org/0000-0001-5331-8221

REFERENCES

[1] EULAR Strategy 2024-2028 Zürich: EULAR; 2023. Available from: https://www.eular.org/eular-strategy. August 8, 2026.
[2] EULAR PARE community. Zürich: EULAR; 2026. Available from: https://www.eular.org/the-eular-pare-community.
[3] Stones S, Richards D, Woollard L, Bharadia T, Oliver J, McSorley S, et al. Involving patients, carers, and patient organizations in European medical congresses. Curr Med Res Opin. 2025;41:4–21.
[4] Aouad K, de Wit M, Elhai M, Benavent D, Bertheussen H, Zabalan C, et al. Patient research partner involvement in rheumatology research: a systematic literature review informing the 2023 updated EULAR recommendations for the involvement of patient research partners. Ann Rheum Dis. 2024;83:1268–77.
[5] de Wit MP, Berlo SE, Aanerud GJ, Aletaha D, Bijlsma JW, Croucher L, et al. European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. Ann Rheum Dis. 2011;70:722–6.
[6] de Wit M, Adebajo A. Unique role of rheumatology in establishing collaborative relationships in research. Past, present and future of patient engagement. Ann Rheum Dis. 2019;78:293–6.
[7] EULAR PARE Study group for collaborative research. Zürich: EULAR; 2017. Available from: https://www.eular.org/web/static/lib/pdfjs/web/viewer.html?file=https://www.eular.org/document/download/282/9b6c234a-fa5e-423a-bf1e-a1c68eadc082/236.
[8] EULAR online training course for patient research partners. Zürich: EULAR; 2024. Available from: https://esor.eular.org/enrol/index.php?id=487.
[9] EULAR Research Consortia Partnerships Zürich: EULAR; 2025. Available from: https://www.eular.org/eular-research-consortia-partnerships. August 8, 2026.
[10] de Wit M, Aouad K, Elhai M, Benavent D, Bertheussen H, Blackburn S, et al. EULAR recommendations for the involvement of patient research partners in rheumatology research: 2023 update. Ann Rheum Dis. 2024;83:1443–53.
[11] de Wit M, Aouad K, Elhai M, Andersen J, Benavent D, Caeyers N, et al. Fostering the future of expanded Patient Research Partner (PRP) involvement in Rheumatology Research. Report of the 2024 EULAR PARE conference. Zürich: EULAR; 2024.
[12] de Wit M, Aouad K, Appel Esbensen B, Boyd P, Caeyers N, Carmona L, et al. Enhancing partnership in research through co-creation: report of the 2025 EULAR PARE Conference. Zürich: EULAR; 2025.
[13] Haywood K, Brett J, Salek S, Marlett N, Penman C, Shklarov S, et al. Patient and public engagement in health-related quality of life and patient-reported outcomes research: what is important and why should we care? Findings from the first ISOQOL patient engagement symposium. Qual Life Res. 2015;24:1069–76.
[14] Haywood K, Lyddiatt A, Brace-McDonnell SJ, Staniszewska S, Salek S. Establishing the values for patient engagement (PE) in health-related quality of life (HRQoL) research: an international, multiple-stakeholder perspective. Qual Life Res. 2017;26:1393–404.
[15] Clemensen J, Rothmann MJ, Smith AC, Caffery LJ, Danbjorg DB. Participatory design methods in telemedicine research. J Telemed Telecare. 2017;23:780–5.
[16] Poncette AS, Rojas PD, Hofferbert J, Valera Sosa A, Balzer F, Braune K. Hackathons as stepping stones in health care innovation: case study with systematic recommendations. J Med Internet Res. 2020;22:e17004..
[17] Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. Health Res Policy Syst. 2020;18:17.
[18] Author Co-Production-Collective. The Value of Co-Production Research Project: A Rapid Critical Review of the Evidence. 2022. URL https://www.coproductioncollective.co.uk/what-is-co-production/value-of-co-production.
[19] Knowles SE, Allen D, Donnelly A, Flynn J, Gallacher K, Lewis A, et al. More than a method: trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production. Res Involv Engagem. 2021;7:34.
[20] Locock L, Boaz A. Drawing straight lines along blurred boundaries: qualitative research, patient and public involvement in medical research, co-production and co-design. Evidence Policy. 2019;15:409–21.
[21] Laidlaw L, Hollick RJ. Values and value in patient and public involvement: moving beyond methods. Future Healthc J. 2022;9:238–42.
[22] Phillips LJ, Nordentoft HM, Pedersen CH, Frølunde L, Olesen BR, Kristiansen M, et al. Tending the tensions in co creation: a critical, reflexive approach to co creative methods. Aarhus, Denmark: Aarhus University; 2013.
[23] Gustafsson A, Naslund H, Markstrom U, Allaskog C, Jenneteg FG, Argentzell E, et al. Tensions as productive forces in coproduced mental health research: an explorative qualitative study. Res Involv Engagem. 2026;12.
[24] Park CH, von Krogh G, Stadtfeld C, Meboldt M, Shrestha YR. Healthcare hackathons as open innovation. Nat Rev Bioeng 2023;1:610–1.
[25] Rigas ES, Kostomanolakis S, Kyriakoulakos N, Kounalakis D, Petrakis I, Berler A, et al. A hackathon as a tool to enhance research and practice on electronic health record systems' interoperability for chronic disease management and prevention. Front Digit Health. 2023;5:1275711.
[26] Stevens MJ, de Wit M, Böhm P, Carmona L, Elhai M, Ferraira R, et al. Implementing Patient Research Partner Engagement in Research (iPREPARE): summary of main findings. Aberdeen: University of Aberdeen; 2025.
[27] Nierse CJ, Schipper K, van Zadelhoff E, van de Griendt J, Abma TA. Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team. Health Expectations. 2012;15:242–54.
[28] de Wit M, Abma T, Koelewijn-van Loon M, Collins S, Kirwan J. 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 2013;3:e003311.
[29] Buerki K, Toitou M, de Wit M, Grealis S, Ludwig S, Britt C, et al. How to build a framework to establish a patient research partner network in rheumatology research: a report of a 2-year implementation project. RMD Open. 2025;11:e005263.

[30] EULAR PARE Guide: starting a patient research partner (PRP) group on a national level. Zürich: EULAR; 2018.
[31] Bird M, Ouellette C, Whitmore C, Li L, Nair K, McGillion MH, et al. Preparing for patient partnership: a scoping review of patient partner engagement and evaluation in research. Health Expect. 2020;23:523–39.
[32] de Souza S, Johansson EC, Karlfeldt S, Raza K, Williams R. Patient and public involvement in an international rheumatology translational research project: an evaluation. BMC Rheumatol. 2022;6:83.
[33] Deming WE. Out of the Crisis. Cambridge, MA: MIT Press; 1982.
[34] Hamilton CB, Hoens AM, McQuitty S, McKinnon AM, English K, Backman CL, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One. 2018;13:e0206588.
[35] Thomsen EL, Esbensen BA, Hansson H, Scheelhardt HVG, Olsen N, Christensen ST, et al. Co-developing a complex transfer intervention with parents: a case study of involvement and parental experience. Res Involv Engagem. 2026;12:20.
[36] Jones C, Hamilton C, Tugwell P, Grosskleg S, Hofstetter C, Horgan B, et al. Implementing the PEIR Framework and PEIRS-22 to facilitate improved and sustainable patient engagement in OMERACT. Semin Arthritis Rheum. 2025;72:152704.
[37] Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, et al. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. Health Expect. 2021;24:863–79.
[38] EULAR. SOPs for EULAR (post-TF) Implementation projects. Zürich: EULAR; 2025. Available from: https://www.eular.org/sops-for-eular-post-tf-implementation-projects.
[39] Loza E, Carmona L, Woolf A, Fautrel B, Courvoisier DS, Verstappen S, et al. Implementation of recommendations in rheumatic and musculoskeletal diseases: considerations for development and uptake. Ann Rheum Dis. 2022;81:1344–7.
[40] Caeyers N. "It's great to see the PRP Network growing". EULAR E-Breakthrough - News from the Standing Committee of People with Arthritis/Rheumatism in Europe EULAR PARE newsletter Breakthrough, EULAR PARE, Zürich, Switzerland, 2016:6.
[41] Korpan C, Galvin T, Van Wingerden C, Bao D, Frandsen N, Stevens C, et al. The Praxis of Belonging at Conferences. A practice guide for those who organise or support conferences to consider building belonging: online, hybrid, or in person. Beyond the Obvious 2025:24. unpublished report.
[42] Aouad K. EMEUNET meets PARE: Strengthening Patient Involvement in Rheumatology. Insights from the 2025 joint meeting on patient involvement and collaborative research, in review; 2026.
[43] Richards DP, Mulhall H, Belton J, de Souza S, Flynn T, Haagaard A, et al. Co-creating and hosting PxP: a conference about patient engagement in research for and by patient partners. Res Involv Engagem. 2024;10:77.
[44] Birch R, Simons G, Wahamaa H, McGrath CM, Johansson EC, Skingle D, et al. Development and formative evaluation of patient research partner involvement in a multi-disciplinary European translational research project. Res Involv Engagem. 2020;6:6.
[45] De Wit M, Beurskens A, Piskur B, Stoffers E, Moser A. Preparing researchers for patient and public involvement in scientific research ± Development of a hands-on learning approach through action research. Health Expect. 2018:1–12.
[46] Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ. 2017;358:j3453.