

Patient research partner engagement in OMERACT: Enhancing engagement through the implementation of patient engagement in research tools

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ABSTRACT

Objectives: This paper describes the evolution and impact of Patient Research Partners (PRPs) in shaping research within OMERACT and provides a framework to enhance their engagement. This session explored one component of a validated framework to evaluate meaningful patient engagement. It provides insights, identifies opportunities for improvement, and recommends using the Patient Engagement in Research (PEIR) Framework, PEIR Plan Guide (workbook), and PEIRS-22 (scale) to guide and measure PRPs' engagement.

Methods: Before the conference, the team held planning sessions and selected the Feel-Valued component of the PEIR Workbook for exploration. During OMERACT 2023, we discussed this topic using the PEIR Plan Guide in an interactive plenary session.

Results: The plenary session produced 72 items from 14 breakout tables addressing PEIR Framework themes.

Conclusions: This paper highlights the role and evolution of PRPs in shaping research within OMERACT. It emphasizes enhancing and accurately measuring PRP engagement through the PEIR Framework, PEIR Plan Guide, and PEIRS-22. The insights and methodologies presented aim to fortify future PRP engagement, ensuring it aligns with OMERACT's principles of patient-centred research.

Introduction

Patients in the arthritis community have been actively engaged in OMERACT research for more than 20 years [1]. Until that time, patients were mainly involved as participants in clinical trials. As patients became more involved in their care, they sought opportunities to lend their voices and perspectives to ensure that patient priorities and outcomes were identified and included in the research agenda.

OMERACT, a global, volunteer-driven, not-for-profit organization, is dedicated to improving outcomes for patients with rheumatic and musculoskeletal diseases by advancing the design and quality of clinical studies and supporting the development of Core Outcome Sets (COS) by identifying areas to be measured (domains) and the corresponding ways

to measure them (instruments) [2].

Though OMERACT was formed in 1992 [3], it became apparent that to honestly know and understand the 'what to measure' in a COS, PRP voices of their lived experience was critical. This led to the attendance of 11 PRPs at the OMERACT 6 conference in 2002 [4]. PRPs have been integrated into the biennial conferences over the next 21 years. PRPs within OMERACT are required members in all active working groups and integral to various committees, bringing invaluable lived experiences and perspective to the development of COS. The extensive OMERACT PRP Network Fig. 1 [5], coordinated by the OMERACT PRP Support Team, represents actively engaged PRPs across numerous working groups, necessitating planning, continuous assessment, and prompt responses to ensure meaningful, sustainable involvement,

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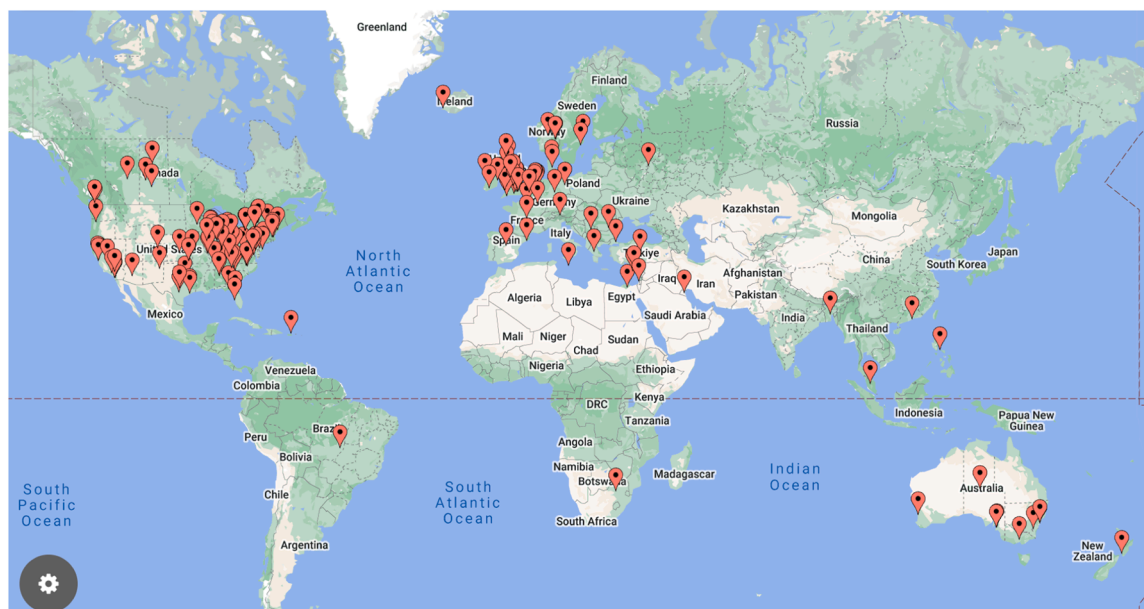


Fig. 1. OMERACT PRP Network.

thereby preserving the quality of the engagement process, and retaining informed PRPs in the working groups.

In OMERACT's ongoing effort to enhance PRP engagement, a reflective process began to assess the state of PRP engagement, gaining valuable insights into both achievements and areas for improvement. This initiative was prompted by a suggestion from one of our PRPs (AH), who introduced the PEIR Framework during a task force exercise.

Hamilton et al. addressed this need by developing: (1) the PEIR Framework - a conceptual framework capturing the key components of patient engagement and how it evolves in research teams [6]; (2) The PEIR Plan Guide [7] - a workbook designed to facilitate discussion within research teams and (3) the PEIRS-22 - an instrument (scale) for assessing effective patient engagement (the PEIRS) [8,9].

This paper illustrates how the PEIR Framework, workbook and scale can enhance and measure the meaningful engagement of PRPs in OMERACT's activities.

Methods

A session on PRP engagement in research was organized for the OMERACT community at the 2023 meeting and led by OMERACT PRPs. The planning team was made up of a group of OMERACT members, including PRPs and the developers of the PEIR Framework. This session started with a presentation emphasizing the role and evolution of PRP involvement in OMERACT, highlighting their contributions to developing COS and participating in various organizational activities. Following the initial presentation, an introduction to the PEIR Plan Guide (workbook for interpreting scores and next steps to improve engagement) and the PEIRS-22 scale were provided. The planning team chose a single component, Feeling Valued, because of its ease of understanding and use in an introductory exercise for the OMERACT community.

The 119 conference attendees, including PRPs, researchers, fellows, clinicians and industry representatives, were seated at tables, which became the breakout groups for the session. Each table included at least one PRP with researchers, clinicians, and other OMERACT collaborators to ensure the opportunity to share diverse perspectives. During the interactive session, members at each table functioned as collaborative teams. The activity revolved around an exercise utilizing the PEIR Plan Guide, wherein teams developed items to enhance the Feel-Valued component of PRP engagement within their respective tables.

The screen displayed an excerpt from the PEIR Plan Guide, providing ongoing reference during the session. Additionally, hard copies of a specific page from the workbook, designed to accommodate up to seven items, were available on each table (Figs. 2-4).

Conference attendees engaged in a 15-minute discussion at their respective tables, articulating their suggested items, focussing on those that would be useable in an OMERACT context. These were recorded on a worksheet. During this activity, tables were asked to focus on the Feeling Valued component of PEIRS. Panel members actively circulated among the tables, lending their expertise and addressing any inquiries posed by participants.

After the activity, the completed worksheets were collected from each table, scanned, and transcribed into an Excel file. Responses were reviewed by a single team member (CH) for content, spelling (corrected as needed), and deciphering of handwritten content.

Once cleaned, the PEIR Framework developer (CBH) began looking for common themes and suggestions across the text fields. The results were collated into items that OMERACT could implement to improve PRPs' Feelings of Value in their work together. All analysis was done in Excel.

Results

The recorded items were diverse and showed a variety of insights. These items spanned from succinct single words like "co-author" to comprehensive sentences such as "Give equal time at meetings/workgroups for opinions, questions, and discussion." Notably, an entry stating "PEIRS" was also included, suggesting that using this framework could make PRPs feel more valued.

Although the task was to focus on Feeling Valued, items were identified that could relate to all eight components found in PEIR. Among these, items coded as relating to Feel-Valued were most prevalent ($n = 24$), followed by "Procedural Requirements" ($n = 19$) and "Contributions" ($n = 15$). Notably, five items traversed two themes. The identified items within Feel-Valued spanned a spectrum, encompassing co-authorship of papers, conference presentations, monetary compensation for participation, acknowledgment during presentations, and charitable contributions. Similarly, "Procedural Requirements" entailed setting expectations, offering feedback to PRPs, and fostering their engagement from project initiation through its entirety.

A tabulated representation of the frequency of themes among the



Fig. 2. Feel-Valued activity description and recommended questions for discussion.

recorded items is provided in Table 1, highlighting the diversity in theme occurrence across the dataset. While the “Feel Valued” concept guided the discussions, participants’ insights extended beyond this focal point, encapsulating other dimensions of meaningful PRP engagement captured by the PEIR Framework. Given their nascent exposure to the framework and theme definitions and being presented with just one component out of the context of the entire framework during the exercise, participants embraced a broader exploration of PRPs’ engagement rather than a singular focus on “Feel Valued.” This approach facilitated an overlap of items across themes, culminating in a comprehensive plan for harmonizing themes and fostering collaborative engagement.

The contribution of items that appear to belong to another

component of the PEIR framework was sometimes attributed to how close the ideas of compensation and support are. In the PEIR Framework, Feel-Valued pertains to monetary and non-monetary compensation, underscoring the importance of valuing PRPs’ contributions. In contrast, “Support” pertains to providing resources enabling engagement, encompassing training, expense reimbursement, and childcare. Nevertheless, some literature has blurred distinct components, conflating support and compensation. This observation underscores the necessity for precise terminology to ensure effective implementation of the PEIR Framework.

Focusing on the Feel-Valued component items, these results show that a well-rounded approach is necessary to effectively engage PRPs in

Items identified for Feel Valued

List two or more items identified for patient partners to feel valued on your project.

Example: Patient partners will be invited to join as co-authors on manuscripts. The team will collectively decide on the degree of participation for all co-authors, including patient partners, in the development of the manuscript.

1	
2	
3	
4	
5	
6	
7	

Fig. 3. Feel-Valued worksheet.

a manner that makes them feel valued.

A dominant item was the concept of "co-author recognition," highlighting the psychological facets of feeling equal, validated, and acknowledged for research contributions. Participants underscored the importance of involving PRPs early in protocol development, study design, and defining domains that matter to the PRP community. Moreover, they expressed the need for authorship recognition and honorariums to accompany this early involvement.

Table 2 presents the strategies identified by participants for improving participation in the Feel-Valued component of the PEIR Framework, organized by thematic categories.

In our subsequent analysis, we categorized all identified items into themes to facilitate an understanding of the items. The themes identified were: "Co-Author Recognition," "Compensation (travel, time)," "Praise and Acknowledgment," and "PRP Led & Focused Presentations." Some items identified by participants had more than one theme so that multiple themes may be attributed to one. This thematic organization aids in understanding the varied items under the Feel-Valued component and

enables the identification of recurring themes,

Discussion

The session aimed to highlight the history of PRP engagement in OMERACT and introduce the PEIR Framework, PEIR Plan Guide and PEIRS-22 to the OMERACT community with a view toward implementation. Completing worksheets by all 14 table teams, generating 72 items, reflected the enthusiasm for and the depth and breadth of items shared by the participants.

The session allowed for a comprehensive exploration of the Feel-Valued component and facilitated direct engagement of attendees, ensuring their active participation in generating action items.

However, the session has some limitations. The relatively small sample size of PRPs, 15 % of total attendees ($n = 18$), might influence the applicability of the findings across a broader context. While the number of PRPs is small, it reflects a typical OMERACT face-to-face meeting, where engaging our PRPs is essential. Additionally,

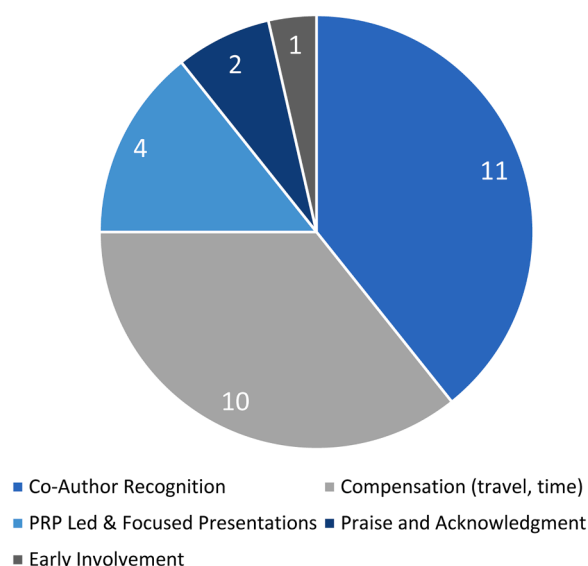


Fig. 4. Common themes identified by participants from "Feel Value" items.

Table 1
Frequency of recorded items across components of PEIR framework.

Component Of PEIR framework	Number of items
Feel Valued	24
Procedural Requirements	19
Contributions	15
Support	5
Team Interactions	4
Research Environment	4
Benefits	4
Convenience	3

participants had restricted familiarity with the PEIR Framework and the definitions of its components. Despite the instructions to participants to focus on "Feel Valued," the results show that they considered a full array of themes from the PEIR Framework. This indicates an implicit understanding that these themes are interrelated and that effective engagement requires a coordinated and comprehensive approach.

Implementing the PEIR Framework, the PEIR Plan Guide as a workbook and the PEIRS-22 as a measurement tool within the OMERACT community marks a significant step towards enhancing and measuring PRP engagement and guiding working group activities. The PEIRS-22 will provide a standardized and quantitative approach to assessing the meaningfulness of PRP engagement [10]. By incorporating all three PEIR components (the framework, workbook, and scale), OMERACT demonstrates its commitment to fostering a culture of PRP-centered research, where PRPs' voices and perspectives are acknowledged and actively integrated into decision-making processes. This implementation signifies a proactive step towards creating an environment where working groups can effectively evaluate and refine their engagement strategies. As OMERACT begins to implement these three tools, it holds the potential to drive continuous improvements in PRP engagement practices, resulting in more impactful research outcomes and a strengthened partnership between PRPs and other collaborators.

The session identified items that could be used within OMERACT to ensure that PRPs feel valued. These insights provide a starting point for the implementation of the tools.

Conclusion

This paper underscores the pivotal role of PRPs in OMERACT and the

significance of measuring and enhancing their engagement. The evolution of PRP engagement from a limited clinical trial participation role to an active voice shaping research is evident. However, the ongoing enhancement of PRP engagement is essential for upholding the quality of their involvement, the retention of experienced PRPs and the integrity of OMERACT's mission.

Introducing the PEIR Framework, PEIR Plan Guide, and PEIRS-22 to the OMERACT community has provided valuable insights into enhancing and measuring meaningful PRP engagement. The plenary session exemplified a targeted approach to engaging conference attendees using the PEIR Plan Guide, fostering collaborative item generation to enhance the Feel-Valued component. The next step for OMERACT will be to survey the active PRPs (approximately 170) with the PEIRS-22 to elicit their perspectives regarding their previous/current engagement with OMERACT. The results will inform strategies to enhance patient engagement within OMERACT.

This paper is a foundation for future efforts to enhance PRP engagement within OMERACT. Implementing the PEIR Framework, PEIR Plan Guide, and PEIRS-22 OMERACT can advance meaningful PRP involvement that aligns with its mission. As OMERACT continues to evolve, this work provides valuable guidance to optimize the engagement process and uphold the principles of PRP-centered research.

CRedit authorship contribution statement

Catherine Hofstetter: Conceptualization, Methodology, Investigation, Writing – original draft. **Shawna Grosskleg:** Conceptualization, Methodology, Investigation, Writing – original draft. **Clayton B. Hamilton:** Conceptualization, Methodology, Investigation, Writing – original draft. **Alison M Hoens:** Conceptualization, Methodology, Investigation, Writing – original draft. **Beverley Shea:** Conceptualization, Methodology, Investigation, Writing – original draft. **Peter Tugwell:** Conceptualization, Methodology, Investigation, Writing – original draft. **Dorcas Beaton:** Conceptualization, Methodology, Investigation, Writing – original draft.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Catherine Hofstetter receives support for attending meetings and/or travel from OMERACT for bi-annual conference.

Peter Tugwell receives consulting fees from Reformulary Group for providing independent medical consultation professional services to the firms listed in this section. Participation on a Data Safety Monitoring Board or Advisory Board for UCB Biopharma GmbH & SPRL Parexel International Prahealth Sciences. Is an independent Committee Member for clinical trial Data Safety Monitoring Boards for FDA approved trials being conducted by:

- UCB Biopharma GmbH & SPRL
- Parexel International
- Prahealth Sciences

Other financial or non-financial interests with Abbvie, Astra Zenaca, Aurinia, BMS, Centrexion, GSK, Horizon Pharma Inc, Janssen, Novartis, Pfizer & Sparrow. He is [unpaid] Chair of the Management Group of a registered non-profit independent medical research organization, OMERACT, whose goal is to improve and advance the health outcomes for patients suffering from musculoskeletal conditions. OMERACT receives arms-length funding from 11 companies.

Dorcas Beaton had a leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid as a member of Management team at OMERACT, co- chair of methods group and technical advisory group of OMERACT.

All other authors have no conflicts to declare.

Table 2
All items from the Feel-Valued component.

Co-Author Recognition
Co-Author Recognition "Recognition, feeling equal, validation" part of the team -> (publications, 8pts? What type)
Co-Authorship in publications
co-authors
Patient-led publications
Attribution to patient contribution to the research
Co-Authorship- opportunity to write a paper from PRP perspective - patients could understand this paper
Active record of their contribution, publications, co-supervisor, giving responsibility
Recognition of PRPs at all presentations of work and allowing co-authorship and recognition
Patients/Parents as Co-Authors on manuscript
Involve patient early in protocol development, study design, what outcomes that matters. What is(remote or office visit), wearables. In addition, authorship and honorarium
Compensation (travel, time)
Involve patient early in protocol development, study design, what outcomes that matters. What is(remote or office visit), wearables. In addition, authorship and honorarium
Provision of travel costs & compensation for time commitment
Support travel funding
Provide support to develop and present findings/ abstracts
\$ - attendance, need \$ direct, indirect
Benefit in kind
Charitable donations as a form of compensation.
Considerations for channels of financial recognition via direct payment VS directed donations
Being treated well (valued, compensated for our time + work)
Co-PI on grants with equal compensation for time and effort
PRP Led & Focused Presentations
Provide support to develop and present findings/ abstracts
Presentations / voices heard
Patient presentations give them a voice
Presentations at conferences -> research from PRP perspectives
Praise and Acknowledgment
Being treated well (valued, compensated for our time + work)
Gratitude, praise (verbal)
Early Involvement
Involve patient early in protocol development, study design, what outcomes that matters. What is(remote or office visit), wearables. In addition, authorship and honorarium

References

- [1] De Wit MPT, Abma TA, Koelewijn-Van Loon MS, Collins S, Kirwan J. What has been the effect on trial outcome assessments of a decade of patient participation in OMERACT? [Article]. *J Rheumatol* 2014;41(1):177–84. <https://doi.org/10.3899/jrheum.130816>.
- [2] OMERACT. (2023, July 28). *Home*. <https://Omeract.Org/>.
- [3] Tugwell P, Boers M. OMERACT conference on outcome measures in rheumatoid arthritis clinical trials: introduction. *J Rheumatol* 1993;20(3):528–30.
- [4] KIRWAN J, HEIBERG T, SUAREZ ALMAZOR M, TAAL E, HEWLETT S, HUGHES R, KVIEN T, AHLMEN M, BOERS M, MINNOCK P, SAAG K, SHEA B. Outcomes from the patient perspective workshop at OMERACT 6 [Article]. *J Rheumatol* 2003;30(4):868–72.
- [5] OMERACT PRP Network. (2023, October 10). 2023.
- [6] Hamilton CB, Hoens AM, Backman CL, McKinnon AM, McQuitty S, English K, Li LC. An empirically based conceptual framework for fostering meaningful patient engagement in research [Article]. *Health Expectat: Int J Public Participat Health Care Health Policy* 2018;21(1):396–406. <https://doi.org/10.1111/hex.12635>.
- [7] Hamilton C.B., Hoens A.M., Backman C.L., English K., McKinnon A.M., McQuitty S., & Li L.C. (2023, July 25). *Workbook to guide the development of a patient engagement in research (PEIR) plan*. <https://www.Arthritisresearch.ca/Wp-Content/Uploads/2018/06/PEIR-Plan-Guide.Pdf>.
- [8] Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, Li LC. Shortening and validating the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement [Article]. *Health Expectat: Int J Public Participat Health Care Health Policy* 2021;24(3):863–79. <https://doi.org/10.1111/hex.13227>.
- [9] Hamilton CB, Hoens AM, McQuitty S, McKinnon AM, English K, Backman CL, Azimi T, Khodarahmi N, Li LC. Development and pre-testing of the Patient Engagement in Research Scale (PEIRS) to assess engagement quality from a patient perspective [Article]. *PLoS ONE* 2018;13(11). <https://doi.org/10.1371/journal.pone.0206588>. e0206588–e0206588.
- [10] Gordon B, Van De Griend KM, Scharp VL, Ellis H, Nies MA. Community engagement in research: an updated systematic review of quantitative engagement measurement scales for health studies [Article]. *Eval Health Prof* 2023. <https://doi.org/10.1177/01632787231203346>. 1632787231203346–1632787231203346.