



Implementing the PEIR Framework and PEIRS-22 to facilitate improved and sustainable patient engagement in OMERACT

Caitlin Jones^{a,*} , Clayton Hamilton^b, Peter Tugwell^{c,j,k}, Shawna Grosskleg^{d,e}, Catherine Hofstetter^f, Ben Horgan^g, Alison Hoens^h, Dorcas Beatonⁱ

^a Institute for Musculoskeletal Health, University of Sydney and Sydney Local Health District, 10N KGV Building, Missenden Road, Camperdown, New South Wales, Australia 2050

^b Faculty of Health Science, Simon Fraser University, Burnaby, British Columbia, Canada

^c Department of Medicine, University of Ottawa, Canada

^d OMERACT, Toronto, Canada

^e Faculty of Medicine, University of Ottawa, Ottawa, Canada

^f Patient Research Partner, Canada

^g Royal Perth Bentley Group, Royal Perth Hospital, Wellington Street, Perth, WA 6000

^h Department of Physical Therapy, Faculty of Medicine, The University of British Columbia, #225, 212 - 2177 Wesbrook Mall, Vancouver, British Columbia, Canada V6T 1Z3

ⁱ Senior Scientist, Institute for Work & Health, Toronto, Canada

^j Bruyere Health Research Institute, Canada

^k Ottawa Hospital Research Institute, Ottawa Canada

ARTICLE INFO

Keywords:

Patient engagement
PEIRS-22
Psychometrics
OMERACT

ABSTRACT

Background: OMERACT (Outcome Measures in Rheumatology) is an international initiative focused on improving outcome measurement in rheumatology research, fostering collaboration among PRPs, clinicians, and researchers to develop Core Outcome Sets. The 22-item Patient Engagement In Research Scale (PEIRS-22) is a tool designed to measure the level of meaningful patient engagement and guide efforts towards improvement.

Aim: 1) To describe the current profile of patient engagement at OMERACT using the scores generated by the PEIRS-22 and 2) to assess the validity of the PEIRS-22 within the OMERACT group of PRPs.

Methods: We administered the PEIRS-22 to assess the level of meaningful engagement of PRPs with OMERACT. We compared the scores with self-rated participant engagement, and asked open ended questions to investigate the validity of the tool in the OMERACT PRP population.

Results: Overall engagement was meaningful and correlated to self-reported level of engagement. However, there were components and items that were flagged as priorities for improvement (Convenience, Benefits and Team Environment, and specifically items PR11: I participated in making decisions about the project, T2: I was an equal partner in the research project team, and SU1: I received sufficient support to contribute to the project.

Conclusion: This study highlights the validity of the PEIRS-22 within OMERACT and reveals satisfactory levels of meaningful PRP engagement. As OMERACT continues to learn and evolve, the PEIRS-22 will be integral in developing a structured and consistent approach to patient engagement.

Introduction

Background

Engagement of people with lived and living experience of health conditions and service needs, as patient research partners (PRPs) in health research, is critical to enhancing research relevance and impact.

OMERACT (Outcome Measures in Rheumatology) is an international initiative focused on improving outcome measurement in rheumatology research, fostering collaboration among PRPs, clinicians, and researchers to develop Core Outcome Sets [1]. OMERACT, a leader in patient-centred research, recognizes the need for continuous assessment and improvement to ensure meaningful engagement with PRPs. Systematic reviews have identified promising tools for evaluating patient

* Corresponding author.

E-mail address: caitlin.jones@sydney.edu.au (C. Jones).

<https://doi.org/10.1016/j.semarthrit.2025.152704>

Available online 27 February 2025

0049-0172/© 2025 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

engagement [2,3]. These tools provide a foundation for better understanding and improving the engagement process. To realize the value of patient engagement to advance research and care, it must be done well. While it is commonly understood that patient engagement should be meaningful rather than tokenistic, there was previously limited explicit conceptualization of what PRPs perceived as meaningful engagement. Given the variability in approaches to engaging PRPs by research leads and co-researchers, a validated framework is needed to optimize the impact of adopting patient engagement in research.

To address this gap, Hamilton and colleagues developed the Patient Engagement In Research (PEIR) Framework and 22-item Patient Engagement In Research Scale (PEIRS-22) to illustrate the aspects of patient engagement that make it meaningful to PRPs. The PEIR Framework and PEIRS-22 were empirically designed through critical analysis of scientific articles and interviews with experienced PRPs [4-7]. It includes a workbook that consists of a comprehensive set of eight organizing themes covering the key elements of meaningful patient engagement [8]. The PEIR Framework is accompanied by the PEIRS-22 scale that can be used to evaluate meaningful patient engagement and identify areas for improvement. OMERACT has partnered with the PEIR team to study current PRP engagement across OMERACT and to develop an implementation plan of the PEIR Framework, guided by the PEIRS-22, to evaluate and enhance PRP engagement at OMERACT.

Aims

- 1) To describe the current profile of patient engagement at OMERACT using the scores generated by the PEIRS-22.
- 2) To assess the validity of the PEIRS-22 within the OMERACT group of PRPs.

Methods

Overview of approach

We conducted an online, anonymous survey to establish a baseline measurement of OMERACT’s status of engagement with PRPs across March and April 2024. The PEIRS-22 scores, along with the PEIR Framework, were used to identify areas where OMERACT resources could be directed to further improve how OMERACT engage PRPs. The participants were PRPs are currently or previously involved with OMERACT working groups. The survey had two parts. The first part used the PEIRS-22 to assess the meaningful PRP engagement in OMERACT working groups. All involved PRPs were asked to share their basic demographics and OMERACT involvement information (type of disease, age, gender, self-rated level of participation in OMERACT, number of years with OMERACT, self-rating of personal engagement in OMERACT working group or OMERACT Community processes and decisions), and to complete the PEIRS-22.



Fig. 1. Components of meaningful engagement according to the PEIRS framework. Source: Hamilton, C. Workbook to guide the development of a Patient Engagement In Research (PEIR) Plan. Used with permission from C.Hamilton.

The second part of the survey asked respondents to reflect on each of the eight components of the PEIR Framework (see Fig. 1). Participants were asked to elaborate on their responses on the seven subdomains of the PEIRS-22 by providing context and examples in a free-text format. Note the two components of the Framework are collapsed into one subdomain in the scale, resulting in seven subdomains [9]. We also asked participants to reflect on how comprehensive PEIRS-22 is at capturing all the feedback they wished to provide and what, if anything, needed to be added. Additional analysis was done by comparing OMERACT involvement ratings versus the PEIRS-22 ratings to obtain more insights on the validity of these tools for implementation at OMERACT.

Criteria for Participation

The criteria for participation in phase 1 were to be a PRP member of OMERACT, and currently or previously involved with at least one working group. OMERACT retains a database of active members, including its PRPs. We invited PRPs listed in the database, updated in 2023, to participate in this study.

Sample size

Given that this was a descriptive rather than analytic study, our goal was to gain a comprehensive view of patient engagement in OMERACT. We, therefore, invited all PRPs to consider participating. 172 PRPs in the OMERACT database met the criteria. The survey was only available in English, the language used in OMERACT meetings, ensuring consistency in communications.

Recruitment methods

Invitations to complete the PEIR-22 were sent via email from the Chair of OMERACT and co-signed by the Chair of the PRP Support Team, to all the PRPs who met the criteria for participation. The email included a participant information statement and a survey link.

Personal identifiers

All survey data were de-identified. We used SurveyMonkey (premium) and set the settings to prevent retention of any identifying information, including IP addresses. This ensured participant anonymity and protected personal data. This approach was used to maintain confidentiality and foster an environment where participants could provide honest, unfiltered feedback without concern for their privacy being compromised. The names and emails used for the mailout were not linkable to the survey responses and were kept separate from them.

Safeguards to protect confidentiality

Survey responses were gathered anonymously. Our research team did not know who responded; no personally identifying information was gathered or retained. Some broad descriptive information was collected, such as years of involvement in OMERACT, type of rheumatic disease, disease duration, etc. We worded descriptors of their participation in OMERACT in such a way as to avoid identifying the specific working group or groups they are involved in, as many working groups currently have only 2–4 PRPs. We avoided presenting information where there were less than five persons in a response category by censoring or collapsing data in response categories with fewer than five participants.

Data analysis

Patient Engagement in OMERACT

The responses to the online PEIRS-22 were scored according to the developers' instructions. The developers describe that the threshold for

low meaningfulness is 70 [9]. For the overall PEIRS-22 score, we report non-parametric descriptive statistics, including the median [IQR], min-max, and proportion of PRPs achieving scores above the threshold. We also present overall scores by gender, number of face-to-face conferences, and self-rated participation. We investigated whether there were substantive and statistically significant differences between groups.

For each of the seven subdomains of the PEIRS-22, we present non-parametric descriptive statistics for the entire sample's scores as median [IQR], min-max, the median as a percentage of the maximum possible score (e.g. standardised to a 0–100 scale). We report whether the group's median was above the threshold for meaningfulness and the proportion of participants who were individually above the threshold for low meaningfulness, as set by the scale developers. We also present scores for each component by the level of self-rated engagement (1. None/tokenistic engagement, 2. Somewhat engaged, 3. Very engaged) and the same descriptive statistics as listed above.

As per the scale's scoring instructions, individual items can be considered as 'bronze' (easiest to achieve), 'silver' (more difficult to achieve), or 'gold' (hardest to achieve). Bronze items are CN4, CT4, PR14, CT2, BE1, and CT1. Silver items are PR2, PR12, PR9, BE2, FV1, T5, SU2, and BE4. Gold items are FV3, T2, PR13, PR11, CN1, PR10, SU1, and CN3. We examined whether 80 % or more PRPs were scoring above the cutoff for low meaningfulness for each item and qualitatively assessed whether OMERACT was achieving meaningful engagement at a bronze, silver or gold level.

Validation Testing and Qualitative Analysis of the PEIRS-22 Responses

To test for floor and ceiling effects, we report the number (%) of people scoring the lowest or highest possible score per subdomain. We considered ≤ 15 % of participants per subgroup scoring at the floor or ceiling acceptable.

Correlations between PEIRS-22 scores and self-rated level of engagement were calculated to evaluate the scale's criterion validity. We hypothesised that those people who identify as being less engaged should have lower PEIRS-22 scale scores. In this context we would hope to see at least a moderate correlation (Spearman-ranked correlation of 0.50 or more) to provide evidence of validity in our setting.

We conducted qualitative analysis on the open-text field question, "Was this survey comprehensive enough for you to give us all the feedback you wanted to give?". We used inductive open coding aiming to get at the main theme of the person's answer, followed by deductive coding to link these themes to the eight domains of the PEIR Framework [10]. One coder (CJ) mapped responses to the eight components, where possible, to be left with a list of responses that could not be mapped to an existing component of the PEIRS-22, which could signal that important perspectives were not addressed by the scale. A second coder (AH) checked the first coder's work, and they reached a consensus on any disagreements. We did not conduct a complete qualitative analysis on the open text response fields that asked participants to elaborate on the reason for their PEIRS-22 scores.

Results

Baseline characteristics

Of the 172 PRPs invited, 68 completed the survey (39.5 %)—eight of those provided only demographic details and did not complete further questions. See Table 1 for participant characteristics. The sample is comparable to the entire OMERACT PRP population in that the majority are from the US followed by the UK, followed by Canada. We are not able to compare other demographic details as we do not have other demographic data from the entire OMERACT PRP besides country of residence.

Table 1
Participant characteristics.

| | N = | % |
|---|-----|----|
| | 68 | |
| Gender | | |
| Female | 48 | 71 |
| Male | 19 | 28 |
| Non-binary/uses a different term | 1 | 1 |
| Country (current) | | |
| Australia | 5 | 7 |
| Austria | 1 | 1 |
| Canada | 12 | 18 |
| Cyprus | 1 | 1 |
| France | 2 | 3 |
| Germany | 1 | 1 |
| Ireland | 1 | 1 |
| Italy | 2 | 3 |
| Malta | 1 | 1 |
| Netherlands | 3 | 4 |
| New Zealand | 1 | 1 |
| Serbia | 1 | 1 |
| Spain | 1 | 1 |
| Türkiye | 1 | 1 |
| United Kingdom of Great Britain and Northern Ireland | 16 | 24 |
| United States of America | 19 | 28 |
| Age in years | | |
| 18 to 25 | 0 | 0 |
| 26 to 40 | 7 | 10 |
| 41 to 65 | 27 | 40 |
| 66+ | 34 | 50 |
| Years of involvement | | |
| 0 to 3 | 22 | 32 |
| 4 to 6 | 27 | 40 |
| 7 to 9 | 6 | 9 |
| 10+ | 13 | 19 |
| Number of face-to-face conferences attended | | |
| 0 | 34 | 50 |
| 1 to 3 | 24 | 35 |
| 4 to 6 | 3 | 4 |
| 7+ | 7 | 10 |
| Self-rated level of engagement | | |
| Not engaged at all. Don't hear from them. | 1 | 1 |
| Engaged in tokenistic manner | 10 | 15 |
| Somewhat engaged (e.g., participate in calls, but don't do anything in between) | 33 | 49 |
| Very engaged in decision-making and processes | 24 | 35 |
| Type of participation (participants could select more than 1 option) | | |
| I am informed about OMERACT activities | 48 | 71 |
| I engage with OMERACT education opportunities | 24 | 35 |
| I am consulted during OMERACT activities | 27 | 40 |
| I am involved in OMERACT processes | 29 | 43 |
| I am a co-designer of OMERACT research/activities | 9 | 13 |
| I am a co-producer of OMERACT research/activities | 4 | 6 |
| I lead OMERACT research/activities | 1 | 1 |

Patient Engagement in OMERACT

Overall PEIRS-22 scale results

Overall, the median PEIRS-22 score was 72.7 out of 100 (IQR = 62.5 to 88.6). Fifty-eight percent of individual participants scored above the low meaningfulness threshold of 70.1. See [Table 2](#) for the overall scores and scores broken down by key characteristics.

PEIRS-22 results by subdomain – overall

Scores for the entire group are presented per component in [Table 3](#). The group's median score was above the threshold of meaningfulness for each component.

PEIRS-22 scale results by component, split by self-rated level of engagement

When the component scores were broken down by the participant's self-rated level of engagement, there was a consistent pattern of lower PEIRS-22 scores for people with lower self-rated engagement. See [Table 4](#).

Table 2
Overall results and subgroups.

| | Median PEIRS-22 scores [IQR] | Min - Max | P value of difference between groups | % of PRPs above low meaningfulness threshold |
|---|------------------------------|--------------|--------------------------------------|--|
| All (n = 60) | 72.7 [62.5 – 88.6] | 19.3 – 100.0 | | 58 |
| Gender* | | | 0.765 | |
| Women* (n = 42) | 72.7 [62.5 – 88.6] | 19.3 – 100.0 | | 60 |
| Men* (n = 18) | 72.7 [64.5 – 84.7] | 50.0 – 93.2 | | 55 |
| Number of face-to-face conferences | | | 0.347 | |
| 0 (n = 29) | 70.5 [62.5 – 78.4] | 48.9 – 96.6 | | 55 |
| 1 to 3 (n = 22) | 79.0 [62.8 – 90.3] | 19.3 – 100.0 | | 59 |
| 4 + (n = 9) | 79.6 [69.3 – 88.6] | 48.9 – 94.3 | | 67 |
| Self-rated participation | | | <0.001 | |
| Participants who said they were not engaged, or only engaged in a tokenistic manner (n = 8) | 54.0 [47.7 – 56.8] | 19.3 – 88.6 | | 13 |
| Participants who said they were somewhat engaged (n = 28) | 69.3 [62.5 – 74.2] | 50.0 – 96.6 | | 46 |
| Participants who said they were very engaged (n = 24) | 88.6 [77.6 – 91.2] | 63.6 – 100 | | 88 |

Excludes 8/68 people who did not complete the PEIRS-22

* Did not include 1 participant who identified as non-binary to prevent their answers from being identifiable

Table 3
Entire groups scores by subdomain.

| Subdomain (maximum score) | Cut-point score for meaningfulness (| Median [IQR] | Min-Max | % of PRPs above threshold for meaningfulness |
|---------------------------|--------------------------------------|------------------|----------|--|
| PR (31.8) | 22.3 | 23.9 [19.3–26.4] | 5.7–31.8 | 62 |
| CN (13.6) | 9.6 | 10.2 [8.0–11.4] | 0.0–13.6 | 62 |
| CT (13.6) | 9.6 | 10.2 [10.0–13.0] | 3.4–13.6 | 79 |
| T (9.1) | 6.4 | 6.8 [5.7–8.0] | 2.3–9.1 | 62 |
| SU (9.1) | 6.4 | 6.8 [5.7–8.0] | 0.0–9.1 | 63 |
| FV (9.1) | 6.4 | 6.8 [5.7–8.0] | 2.3–9.1 | 53 |
| BE (13.6) | 9.6 | 10.2 [8.0–13.0] | 1.1–13.6 | 55 |

PR – Procedural requirements

CN - Convenience

CT - Contributions

T – Team environment and interaction

SU - Support

FV – Feeling valued

BE – Benefits

Table 4
Scores per component split by self-rated level of engagement.

| Level of engagement | Median [IQR] | Min-Max | Position relative to low meaningfulness cut point | Median as a percentage of maximum possible score | % of PRPs above threshold for low meaningfulness |
|--|--------------------|-------------|---|--|--|
| PR (maximum score is 31.8, low meaningfulness cut point is 22.3) | | | | | |
| Not/Tokenistic | 15.9 [13.4 - 19.6] | 5.7 - 26.1 | Below | 50 | 13 |
| Somewhat | 22.7 [19.0 - 24.1] | 13.6 - 30.7 | Above | 71 | 57 |
| Very | 27.8 [23.9 - 29.5] | 18.2 - 31.8 | Above | 87 | 83 |
| CN (maximum score is 13.6, low meaningfulness cut point is 9.6) | | | | | |
| Not/Tokenistic | 7.4 [6.5 - 8.5] | 2.3 - 11.4 | Below | 50 | 25 |
| Somewhat | 9.1 [8.0 - 10.2] | 3.4 - 13.6 | Below | 67 | 43 |
| Very | 11.4 [10.2 - 12.8] | 8.0 - 13.6 | Above | 84 | 96 |
| CT (maximum score is 13.6, low meaningfulness cut point is 9.6) | | | | | |
| Not/Tokenistic | 8.5 [7.4 - 9.1] | 3.4 - 13.6 | Below | 63 | 13 |
| Somewhat | 10.2 [9.1 - 10.5] | 6.8 - 13.6 | Above | 75 | 71 |
| Very | 12.5 [11.1 - 13.6] | 10.2 - 13.6 | Above | 92 | 100 |
| T (maximum score 9.1, low meaningfulness cut point is 6.4) | | | | | |
| Not/Tokenistic | 4.0 [3.1 - 6.0] | 2.3 - 9.1 | Below | 44 | 25 |
| Somewhat | 6.3 [4.6 - 6.8] | 3.4 - 9.1 | Below | 75 | 50 |
| Very | 8.0 [6.8 - 8.2] | 5.7 - 9.1 | Above | 88 | 88 |
| SU (maximum score 9.1, low meaningfulness cut point is 6.4) | | | | | |
| Not/Tokenistic | 4.6 [4.3 - 6.3] | 2.3 - 8.0 | Below | 51 | 25 |
| Somewhat | 6.8 [5.7 - 6.8] | 2.3 - 9.1 | Above | 75 | 57 |
| Very | 8.0 [6.8 - 9.1] | 4.6 - 9.1 | Above | 88 | 83 |
| FV (maximum score 9.1, low meaningfulness cut point is 6.4) | | | | | |
| Not/Tokenistic | 4.6 [4.3 - 5.7] | 2.3 - 9.1 | Below | 51 | 13 |
| Somewhat | 6.3 [5.7 - 6.8] | 3.4 - 8.0 | Below | 75 | 59 |
| Very | 8.0 [5.7 - 9.1] | 4.6 - 9.1 | Above | 88 | 71 |
| BE (maximum score 13.6 low meaningfulness cut point is 9.6) | | | | | |
| Not/Tokenistic | 7.4 [4.3 - 8.2] | 1.1 - 11.4 | Below | 54 | 13 |
| Somewhat | 9.1 [8.0 - 10.2] | 6.8 - 13.6 | Below | 75 | 39 |
| Very | 11.4 [10.2 - 13.6] | 8.0 - 13.6 | Above | 84 | 88 |

PR – Procedural requirements
 CN - Convenience
 CT - Contributions
 T – Team environment and interaction
 SU - Support
 FV – Feeling valued
 BE – Benefits

Bronze, silver and gold levels

We looked at the proportion of PRPs affirming a positive experience on each item of the PEIRS-22. The results show that above 90 %, above 80 %, and between 87–79 % of PRPs affirmed a positive experience on items of the bronze, silver, and gold level of meaningful engagement, respectively. This suggests that OMERACT is performing well in the most easily achieved items, less well in the silver items, and with mixed results in some gold items.

This suggests that OMERACT is performing well in the most easily achieved items, less well but still above the threshold for meaningfulness in the silver items, and that there is room for improvement in some gold items. Three items in particular had only 79 % of PRPs reporting meaningful engagement; PR11: I participated in making decisions about the project, T2: I was an equal partner in the research project team, and SU1: I received sufficient support to contribute to the project (for example, orientation, readings, training workshops, webinars. Other items that were close to the cut point with 81 % of respondents affirming positive experiences were PR13: Communication within the research team was clear throughout the project, CN1: I had the opportunity to provide input into selecting my tasks for the project, FV3: I was offered sufficient recognition for my contributions (for example, payment, authorship, or gifts), BE2: I made an impact on the decisions in the project, and BE4: My involvement had positive impacts on my life.

Validation of the PEIRS-22

Quantitative validation of the PEIRS-22 in this population

There was no evidence of floor or ceiling effects overall or in any subgroup. The PEIRS-22 scores had a moderate positive correlation (Spearman’s $r = 0.60$, $p < 0.001$). When one outlier was removed (suspected error by participant, very high PEIRS-22 score combined with the lowest possible self-rated engagement score), the correlation was strong (Spearman’s $r = 0.70$, $p = <0.001$). One-way ANOVA (Kruskal-Wallis) found a significant positive relationship ($p < 0.001$) between total PEIRS-22 scores and self-rated level of engagement.

Responses to the question “Was this scale comprehensive enough for you to give the feedback you wanted to give?” are shown in Table 5.

Table 5
Quantitative responses to comprehensiveness question.

| Is this survey comprehensive enough to give us the feedback you want to give? | Counts | % of Total |
|---|--------|------------|
| Strongly disagree | 2 | 3 % |
| Disagree | 9 | 15 % |
| Neutral | 12 | 20 % |
| Agree | 27 | 45 % |
| Strongly Agree | 10 | 17 % |

Qualitative validation of the PEIRS-22 in this population

We received 35 free text responses elaborating on whether participants felt the PEIRS-22 was comprehensive enough to provide the feedback they wanted to give. Eighteen were suggestions for more questions that could be mapped back to subdomains of the PEIRS-22, indicating they are not gaps in the scale.

Of the 15 responses that could not be mapped back to an existing PEIRS-22 subdomains, 11 were suggestions that in the OMERACT context respondents would have preferred to provide separate scores for different working groups (e.g. some PRPs work across multiple groups and would have preferred to provide different feedback for each) or the same working groups across different periods of time (e.g. covid impacted years, various stages of core outcome set development). Two responses suggested an extra question could be asked about the PRP's plans for future involvement with OMERACT. One suggested that the wording of some questions/descriptions might be beyond the reading comprehension level of some PRPs. One was not applicable (irrelevant to PRP engagement for the PEIRS-22).

Discussion

Patient Engagement in OMERACT

PEIRS-22 provided evidence that this sample of PRPs is generally meaningfully engaged with OMERACT activities. The overall group median was above the threshold for low meaningful participation for both the overall scale score and subdomain scores. No subdomain stood out as being scored notably better or worse than others when considering the group as a whole. When broken down by self-rated level of engagement, there was a clear pattern of lower engagement scores associated with lower PEIRS-22 scores. All the PRPs who self-identified as not/tokenistically engaged where below the threshold in all components, as expected. The lowest scored components for the 'somewhat' engaged subgroup were Convenience, Benefits and Team Environment. These are the areas where OMERACT should focus on during future efforts to increase meaningful patient engagement. Specific items that will be priorities for interventions are those listed above in section 3.4.2 that had the lowest proportion of PRPs affirming a positive experience.

Validity of the PEIRS-22

The PEIRS-22 obtain validation for other populations and performed well in measuring patient engagement in research activities in this group of OMERACT PRPs. There were no floor or ceiling effects, and the scale scores correlated as hypothesised with self-rated level of engagement (not/tokenistically/somewhat/very engaged). More than 60 % of respondents thought the scale was comprehensive enough, with a further 20 % being neutral and <20 % disagreed that the scale was comprehensive enough. The free-text feedback revealed that most of the concerns in the free text could be mapped back to an existing PEIRS-22 subdomains and were, therefore, not areas where the PEIRS-22 was lacking. Most free text feedback that could not be mapped back to the PEIRS-22 subdomains were about how to administer the PEIRS-22. Specifically, repeating the scale for each working group (and potentially time period) the PRPs worked across. We considered this while designing this research project; however, we decided not to ask PRPs to identify their working group as that would forfeit their anonymity (most working groups only have ~2 PRPs, so their responses would be identifiable).

Comparison to other research

Two other groups have used the PEIRS-22 alongside other measures of patient engagement to investigate the validity of the tool in their study population. A subgroup of Cochrane found high PEIRS-22 scores in PRPs co-producing systematic reviews of patient decision aids for any

condition, corroborated by qualitative data [11]. This study also examined validity and found favourable metrics similar to ours. Another group translated the PEIRS-22 into Danish and found high levels of meaningful patient engagement in Danish patients working in the cancer space, which focus groups also corroborated [12]. These studies, along with ours, provide increasing evidence that the tool is likely valid in various PRP populations.

Limitations

This project captured to views of ~40 % of the total population of OMERACT PRPs, and therefore may not be representative. Aside from country of residence, we were not able to compare sample and population characteristics. Another limitation is many participants preference for answering the PEIRS-22 per working group. Participants who have experience from multiple working groups may have found it difficult to answer in ways that reflected the breadth of their experience with different OMERACT working groups.

Future directions

Within OMERACT, efforts will continue to attempt to improve meaningful patient engagement. Priority areas will be the PEIRS-22 items with the lowest percentage of PRPs above the threshold for meaningfulness. OMERACT will use the specific free-text feedback provided alongside the scale responses to help guide actions. However, it was beyond this project's scope to report on systematic analysis of those responses.

Other groups considering using the PEIRS-22 to assess their patient engagement activities could ask respondents to identify which specific project/working group they are reporting and whether the group has enough PRPs to enable anonymity. PRPs' desire to give different scores for different projects/groups indicates that their experience is at least partly dependent on the individuals they work with and the requirements of the tasks.

Conclusion

This study highlights the successful application of the PEIRS-22 within OMERACT, revealing satisfactory levels of meaningful PRP engagement. While most PRPs reported meaningful engagement, improvements are needed in areas such as Feeling Valued, and Benefits. As OMERACT continues to learn and evolve, the PEIRS-22 will be integral in developing a structured and consistent approach to patient engagement. The lessons learned here will inform improvements within OMERACT and provide a model for other research organizations aiming to enhance PRP engagement.

Funding

CIHR-IMHA Inclusive Research Excellence Prizes – Patient Engagement competition entitled, "Listening to Patient Partners - From developing evidence-based tools for advancing meaningful patient engagement in research to now implementing them at an international organization for rheumatology research".

Ethics approval

Obtained by the University of Ottawa, Ethics approval number H-02-24-10030 - REG-10030

CRedit authorship contribution statement

Caitlin Jones: Formal analysis, Writing – original draft. **Clayton Hamilton:** Formal analysis, Writing – review & editing, Conceptualization. **Peter Tugwell:** Conceptualization, Writing – review & editing.

Shawna Grosskleg: Conceptualization, Data curation, Writing – review & editing. **Catherine Hofstetter:** Conceptualization, Data curation, Writing – review & editing. **Ben Horgan:** Conceptualization, Writing – review & editing. **Alison Hoens:** Conceptualization, Formal analysis, Writing – review & editing. **Dorcas Beaton:** Methodology, Writing – review & editing, Conceptualization.

Declaration of competing interest

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

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 8 companies.

Dorcas Beaton has an unpaid leadership role as a member of the Management team at OMERACT, co-chair of the methods group, and technical advisory group of OMERACT.

Alison Hoens received financial support to attend the American Occupational Therapy Foundation <https://www.aotf.org/Research-Resources/Engage-Summit> to present on the PEIRS-22.

Clayton Hamilton holds intellectual property/copyright for the PEIRS-22 scale but does not gain financially from it.

Caitlin Jones received payment for her time to undertake the work presented in this manuscript, funded by a Canadian Institutes of Health Research grant.

Appendix 1. Open-ended responses from comprehensiveness questions, mapped to a component of the PEIRS-22 where possible

| Open-Ended Response (direct wording from PRP) | Component(s) of PEIRS-22 |
|--|--|
| The survey encompasses all projects I am / have been involved in. Some WG might be better than others in effectively engaging with PRPs. I'm not sure there are questions in the survey which will allow me to say 'yes, most groups were good / great, but one or two groups don't adequately understand how to effectively work with PRPs'. | Not mapped to PEIRS-22 |
| This survey should be conducted for EACH working group a PRP has participated in, not a combined score for all PRP participations. Some WGs were very inclusive while others were NOT. | Not mapped to PEIRS-22 |
| I seemed to be missed out of communications about any projects. I live in a different country to the team am attached to - nowhere in the survey is there an opportunity to say my responses relate to the fact I may well have missed some communications | PR |
| Perhaps an estimate of time spent on OMERACT activities? | CN |
| No opportunity to distinguish between busy times involved in a project and part of a research study and other ones when not in an action group and not much happening | Not mapped to PEIRS-22 |
| At times I find the sessions go by very quickly and at times more time required on the presentation show of slides. do not feel part of the process yet | CN |
| A question regarding the drop off the email chain and the patient thinking where did that group go? | PR, CN, T, FV, BE |
| Greater clarification of the role/contribution of the patient and the role/contribution of the doctor | PR |
| PRPs may feel they have a lack of understanding about research methodology, graph presentations etc. | SU |
| It would be useful to be able to articulate what difference my engagement made from my point of view. We should also ask our researchers about what difference they felt the PRPs made. | CT, BE, and potentially room for a survey for other team members about the PRPs' input |
| Difficult to decide on response when I've mainly done surveys and one zoom study meeting during Covid. I did enjoy and value that | PR |
| Discussion of [REDACTED FOR ANONYMITY] and its impact on patients experience and treatment choices | Not mapped to PEIRS-22 |
| OMERACT is not a research project, it is a research initiative comprising the work of many working groups with strongly varying characteristics of PRP involvement. I have varying experiences, good as well as poor experiences. They are not captured (yet) by this survey. | Not mapped to PEIRS-22 |
| I am on multiple projects. Some work better than others. Should have asked re frame of reference for OMERACT as a whole, best working group, or worst working group | Not mapped to PEIRS-22 |
| Perhaps include / acknowledge that the time and energy required by PRPs can come at a cost. We willingly give our time and pace our energy. The cost is we have less energy for other important areas of our lives. | FV |
| You now know that I didn't feel that my participation was worth my time and that I didn't feel that I had any impact on the project. You don't know why. I will explain briefly below. | PR |
| The group I am involved in has been going a long time and whilst I still want to remain part of the group and participate where I can contribute and be useful, most of the meetings are very technical and I don't feel that I contribute anything very much. I support a lot of research in [REDACTED FOR ANONYMITY] and am PPI lead in some studies so it's not that I don't have ongoing contact & involvement with the rheumatology research community generally, but I do find the OMERACT meetings difficult to keep up with the language used and don't feel as if I'm contributing much. It was a long time ago that I went to an OMERACT meeting and having [REDACTED FOR ANONYMITY] myself, found the conference difficult to manage physically due to the hours and early start. I think that there needs to be an option for free text to explain more that purely selecting an item on a Likert scale. | PR, CN, CT, SU, BE |
| There could have been some questions about future involvement | Not mapped to PEIRS-22 |
| Being in [REDACTED FOR ANONYMITY] the tyranny of distance applies with OMERACT teams and management very orientated towards the US or Europe. | PR |
| maybe a question on future involvement with OMERACT research? | Not mapped to PEIRS-22 |
| When involved in many projects over the years answers had to be given as an overall judgement rather than for one specific project as the survey seems to refer to . | Not mapped to PEIRS-22 |
| 1. Chance to explicitly identify how many OMERACT initiatives I've been involved in and role (e.g., Delphi respondent, reader of draft publications). | Not mapped to PEIRS-22 |
| 2. Identify main arthritis confirmed diagnosis I have received/live with (e.g., RA, OA). | Not mapped to PEIRS-22 |

(continued on next page)

(continued)

| Open-Ended Response (direct wording from PRP) | Component(s) of PEIRS-22 |
|---|--------------------------|
| 3. Be more specific around what "support" was offered AND whether you chose to take advantage of it. | SU |
| I felt some of the questions were not applicable to me so I have inserted neutral in those questions. Perhaps a N/A alternative would be useful? | Not mapped to PEIRS-22 |
| Covid and distance limited my ability for face-to-face contact at OMERACT meetings. Zoom worked very well for group activities. | PR |
| probably need to spend more time with training modules | SU |
| I was not always sure of what was expected of me. In reviewing the questions for the Delphi, I knew that I was able to make them more understandable to the lay person but on the medical issues I was not sure of what I could contribute beyond my own experience with [REDACTED FOR ANONYMITY]. | PR |
| to what extent do some PRPs feel patronised by the professionals in the group especially in the area of clinical methods and clinical language. | T |
| Where PRPs have multiple levels of involvement it is difficult to answer so possibly suggesting this is focused on a main working group (which I have done here) | Not mapped to PEIRS-22 |
| I am a professional with degrees in [REDACTED FOR ANONYMITY]. Although I was asked about my experiences as a patient, nobody was the least bit interested in hearing what I had to say about the science and about the procedures. As I am retired, I was hoping to find some way of making a real contribution and I thought OMERACT would enable me to do so. Perhaps that was naive of me. | FV |
| I have increasing felt isolated from OMERACT and doubt my continuation. | T |
| As the Working Groups don't always use a standardized approach to PRP Engagement, it's difficult to generalize about experiences. | Not mapped to PEIRS-22 |
| Some Qs and descriptions are probably well above the reading comprehension levels of some PPs. | Not mapped to PEIRS-22 |

References

- [1] Boers M, Kirwan JR, Wells G, Beaton D, Gossec L, d'Agostino MA, et al. Developing core outcome measurement sets for clinical trials: OMERACT filter 2.0. *J Clin Epidemiol* 2014;67(7):745–53.
- [2] 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. *Eval Health Prof* 2023;46:291–308. SAGE Publications Inc.
- [3] Mrklas KJ, Boyd JM, Shergill S, Merali S, Khan M, Nowell L, et al. Tools for assessing health research partnership outcomes and impacts: a systematic review, 21. *Health Research Policy and Systems*. BioMed Central Ltd; 2023.
- [4] Hamilton CB, Hoens AM, Backman CL, McKinnon AM, McQuitty S, English K, et al. An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expect* 2018;21(1):396–406.
- [5] 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(11). e0206588–e0206588.
- [6] 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(3):863–79.
- [7] Christiansen MG, Pappot H, Hamilton C, Lund-Jacobsen T, Kristensen AW, Nordentoft S, et al. Patient engagement in Research Scale (PEIRS-22): danish translation, applicability, and user experiences. *Res Involv Engagem* 2023;9(1). Dec 1.
- [8] Hamilton CB, Hoens AM, Backman CL, English K, McKinnon AM, McQuitty S, et al. <https://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf>. 2023. Workbook to guide the development of a patient engagement In Research (PEIR) Plan.
- [9] Hamilton CB, Hoens Alison M, McKinnon AM, Hawke LD, McQuitty S, English K, et al. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. *Health Expectations* [Internet] 2021;24:863–79. Available from: <https://onlinelibrary.wiley.com/doi/10.1111/hex.13227>.
- [10] Dejonckheere M, Vaughn LM. Semistructured interviewing in primary care research: a balance of relationship and rigour. *Fam Med Com Health* [Internet] 2019;7:57 [cited 2023 Mar 9] Available from: <http://fmch.bmj.com/>.
- [11] Lewis KB, Smith M, Stacey D, Carley M, Graham ID. Evaluation of an integrated knowledge translation approach used for updating the Cochrane Review of Patient Decision Aids: a pre-post mixed methods study. *Res Involv Engagem* [Internet] 2024;10(1). Dec 1 [cited 2024 Aug 21] Available from: <https://pubmed.ncbi.nlm.nih.gov/38331835/>.
- [12] Christiansen MG, Pappot H, Hamilton C, Lund-Jacobsen T, Kristensen AW, Nordentoft S, et al. Patient engagement in Research Scale (PEIRS-22): danish translation, applicability, and user experiences. *Res Involv Engagem* [Internet] 2023;9(1). Dec 1 [cited 2024 Aug 21] Available from: <https://pubmed.ncbi.nlm.nih.gov/38062535/>.