Using the Patient Engagement in Research (PEIR) Framework and Scale to measure the quality of patient engagement

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To strengthen patient-researcher partnerships, we need researchers who know how to partner with people with lived experience.
The experiences of being patient partners

1. Being heard - A partnership is a two-way street

2. “Adding another spinning plate to an already busy life”

3. Seize opportunities to build a trusting relationship

Leese et al., *BMJ Open*, 2018

Jenny Leese
Meaningful patient engagement in research

... the planned, supported, and valued involvement of patients/public in the research process, with individuals perceiving it as a rewarding and productive experience

Hamilton et al., *Health Expectations*, 2018

Kelly English  |  Annette McKinnon  |  Shanon McQuitty  |  Clayon Hamilton
Patient Engagement in Research (PEIR) Framework

- 1. Procedural Requirements
- 2. Research Environment
- 3. Team Interaction
- 4. Convenience
- 5. Contributions
- 6. Support
- 7. Feel Valued
- 8. Benefits

Meaningful Patient Engagement in Research

Hamilton et al., *Health Expectations*, 21(1), 396-406, 2018
**Example 1 – I-START Project (Dr. Jasmin Ma)**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>Does the plan to support your involvement in the project work for you?</td>
<td></td>
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<tr>
<td>Do you have everything you need to contribute to this project?</td>
<td></td>
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<tr>
<td>How do you feel about the overall tone of the team?</td>
<td></td>
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<tr>
<td>Is there anything you would like to change about your current involvement?</td>
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</tbody>
</table>

Jasmin Ma
How do we know if the effort of engaging with patients works?
The Patient Engagement In Research Scale (PEIRS-22) is a valid and reliable questionnaire for assessing the degree of meaningful patient and family caregiver engagement in research from a patient partner perspective. The PEIRS-22 is comprised of 22 questions that reflect 8 themes of meaningful engagement in research. It enables standardized assessment of engagement in research across various contexts. There is no cost to use the PEIRS-22.

Please complete the form below to register your use of the PEIRS-22. You will then get a link to the scale.

Your information will help us keep track of the use of the PEIRS-22. Our team will not share your contact information outside of our project unless legally obliged to do so.
Example 2 –

Patient partner survey → Open-ended question analysis → Identified strength & opportunities → PEIRS-22 data analysis → 14 actionable recommendations → Post-workshop survey → Virtual deliberative dialogue workshop
Analysis of open-ended questions - 3 themes

1. **Communication**: successes, changes and improvements
2. A respectful and welcoming environment
3. **Opportunities** to learn and contribute

Li et al., *Facet*, 2022
Opportunities for Growth

• Take a deliberate (planned) approach to involving patient voices in decision-making

• Expand on outreach strategy to recruit a more diverse group of patient partners that better reflects Canada’s ethnic diversity

• Continue to support a diverse group of patient partners to join at different levels of the SPOR Evidence Alliance’s operation

• Ensure more timely payment of patient partner appreciation (compensation)
SPOR Evidence Alliance
Patient Engagement Evaluation Workshop

Friday, February 4, 2022
Recommendations (Themes)

1. Setting expectations for all team members
2. Building trust and ongoing communication
3. Providing opportunities to enhance learning and to develop skills
4. Acknowledging contributions of patient partners

Ellen Wang  Thalia Otamendi  Clayon Hamilton

Wang et al., Journal of Clinical Epidemiology, 2023
Reflections

• Address power by examining what is meaningful to the partners.
• Relationships evolve over time, so does what is deemed to be meaningful to partners.
• Qualitative data and conversations helps us understand the why, the how, and the context.
• Numbers can help to identify what works (or works better) across similar context.
• Numbers can also inform deeper conversations to improve partner engagement in research.
Thank you!