Measuring the quality of patient engagement as partners on research projects

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BC Ministry of Health

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Learning objectives

- Understand the rationale for measuring the quality of patient engagement
- Identify components of good quality engagement
- Identify tools to measure the quality of patient engagement
Definition: Measure

- **Verb**: “Ascertain the size, amount, or degree of (something) by using an instrument or device marked in standard units.”

- **Noun**: “A standard unit used to express the size, amount, or degree of something”

Definition: patient engagement in research

“Patients taking part in hands-on, decision-making, and advisory activities beyond the role of study participants at any and all stages of the research process.”

### Levels of Patient and Researcher Engagement in Health Research

<table>
<thead>
<tr>
<th>Patient's Goal</th>
<th>Learn/Inform</th>
<th>Participate</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Lead/Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>To ask questions and learn about how to get more involved</td>
<td>To ask as a subject or participant in a research study</td>
<td>To act as a research study</td>
<td>To provide feedback and advice on specific research activities</td>
<td>To work directly with a research team throughout the project</td>
<td>To partner on equal footing with researchers in all aspects of research</td>
<td>To make final decisions and lead research activities</td>
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<th>Researcher's Goal</th>
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<tr>
<td>To provide information, listen, and answer questions honestly</td>
<td>To act ethically and respectfully in the conduct of research</td>
<td>To seek your input on an ad hoc basis</td>
<td>To include you as standing members in an advisory capacity</td>
<td>To partner equally with you as team members</td>
<td>To follow your lead and support your decisions</td>
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<th>How This Can Be Done</th>
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<td>In an open atmosphere for sharing through orientation and information sessions, and media campaigns</td>
<td>Through quantitative, qualitative, or mixed methods research</td>
<td>Through scientific calls, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels</td>
<td>As members of standing working groups and advisory committees or panels</td>
<td>Patients as co-investigators and research partners, and as members of research steering committees</td>
<td>Through patient or community steering committees and patients as principle investigators</td>
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Amirav I et al. (2017) *Pediatrics*:140
**PATIENT-ORIENTED RESEARCH:**

- Engages **PATIENTS AS PARTNERS**
- Focuses on **PATIENT-IDENTIFIED PRIORITIES** to improve **PATIENT-CENTRED OUTCOMES**
- Is conducted by multidisciplinary teams in partnership with **RELEVANT STAKEHOLDERS**
- Aims to apply **KNOWLEDGE GENERATED** to improve healthcare systems & practice

*Increase the QUALITY & IMPACT*
Strategy for Patient Oriented Research (SPOR)
Patient Engagement Framework

Patient engagement is “Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation.”

https://cihr-irsc.gc.ca/e/48413.html
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Amirav I et al. (2017) *Pediatrics*:140
Outline

1. **Why** measure the quality of patient engagement in research?

2. **What** aspects of patient engagement in research could we measure?

3. **How** could we measure these aspects?

4. **When** is a good time to administer the measurement tools?
1. Why

Measure the quality of patient engagement in research?
Current State

- Increasingly being *promoted*, *practiced* and *studied*
- Increase the quality, relevance, and appropriateness
- Validated measurement tools are needed
Rationale

- Identify effective engagement methods
- Improve the quality of partnerships on individual research projects
- Improve the quality of partnerships across research networks and initiatives
- Assess associations between research outcomes and the quality of engagement
- Move beyond lessons learned
2. What

Aspects of patient engagement in research could we measure?
Guiding Principles

- Inclusiveness
- Support
- Mutual Respect
- Co-Build

SPOR Patient Engagement Framework
http://www.cihr-irsc.gc.ca/e/48413.html#a7
Meta-Criteria of effective engagement

- Respect
- Trust
- Legitimacy
- Fairness
- Competency
- Accountability

Dimensions of measurement and evaluation

- Context – “the environment and conditions that underpin and support engagement”
- Process – “how engagement is implemented”
- Impact – “the intended effects of engagement”

Patient Engagement In Research (PEIR) Framework
Patient Engagement In Research (PEIR) Framework

Meaningful Patient Engagement in Research

- Benefits
- Conveniences
- Feel Valued
- Contributions
- Research Environment
- Support
- Team Interaction

Benefits

- Provided renewed purpose and led to a positive change in life
  
  “An arthritis diagnosis can make you feel powerless but collaborating with researchers that listen to and appreciate your feedback gives you some of that power back; personally, it made me feel as though I was contributing to finding answers for people with this disease.” (Lori)

Definition: Meaningful patient engagement

The planned, supported, and valued involvement of patients in the research process, which facilitates their contributions and is a rewarding experience.

Spectrum of quality engagement

Good quality engagement: meaningful to patient partners on research projects.
Key Point 1

PEIR Framework provides the key components of patient engagement for evaluating meaningful engagement from a patient partner perspective.
3. How
Could we measure these aspects of patient engagement in research?
Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective

Clayon B. Hamilton1,2,*, Alison M. Hoens1,3,4, Shanon McQuitty3, Annette M. McKinnon4, Kelly English5, Catherine L. Backman2,5, Tara Azimi2, Negar Khodarahimi2, Linda C. Li1,2,4


* chamilton@arthritisresearch.ca
Three phases of development and validation

Create Items
- 18 Participants
- 18 Publications
- 120 items

Refine & Select
- 12 Participants
- 43 items

Pre-test (Validate)
- 12 Participants
- 37 items

Patient Engagement In Research Scale (PEIRS)

- **Benefits**: 4 points
  - I had opportunities to express my views

- **Convenience**: 4 points
  - The research team members were properly introduced to each other

- **Feel Valued**: 3 points
  - I saw how my contributions could benefit others

- **Procedural Requirements**: 14 points
  - The research project team appreciated my contributions

- **Meaningful Patient Engagement in Research**: 5 points
  - Team Environment and Interaction
Patient Engagement In Research Scale - PEIRS

Name: __________________________
Date: __________________________
Your project's name: __________________________

INSTRUCTIONS: Thinking about your experience as a patient partner in the project, please respond to the statements by ticking only one box for each statement. If you are unsure about which option to choose for a statement, please give the best response you can. This questionnaire may take you about 10 to 15 minutes to complete.

Procedural Requirements

The following fourteen (14) statements are about your general experiences throughout the project.

PM1. I was interested in the issues being researched in the project.
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

PM2. The research team members were properly introduced to each other.
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

PM3. The number of patient partners on the research project team seemed appropriate.
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

PM4. I understood the objectives of the project.
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

PM5. I agreed with the objectives of the project.
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

PEIRS © 2008 C. Marshall & J. All rights reserved.
Overview: Patient Engagement In Research Scale (PEIRS)

- 37 items, 5-point Likert response scale
- 7 subscale, 8 themes
- “Thinking about your experience as a patient partner in the project…”
- 10 – 15 minutes to complete
- Free access – www.arthritisresearch.ca/PEIRS

Key Point #2

PEIRS is the first tool developed to measure the degree of meaningful patient engagement in research.

Importantly, PEIRS was co-built with patient partners who engaged throughout all stages of its development to ensure it is grounded in a patient partner perspective.
The Patient Engagement In Research Scale (PEIRS) Study

Are you 18 years or older and have experience as a member of a research project team?

Please help us test a survey to improve the roles of patients and caregivers on research teams

This online survey takes 15 minutes!


Chance to win a $50 gift card!

Clayon Hamilton, PhD
University of British Columbia
chamilton@arthritisresearch.ca
Other evaluation tools

- Systematic review
ASSESSMENT GRID

We provide a five-point rating for each of the following four criteria:

- **Scientific Rigour**: Was the development of the evaluation tool scientifically rigorous and based on existing evidence on patient and public engagement?
- **Patient and Public Perspective**: Does the evaluation tool take into account the views of patients and the public (both in its development and use)?
- **Comprehensiveness**: Is the tool comprehensive in evaluating the context, process, outcomes and impacts of patient and public engagement?
- **Usability**: Is the evaluation tool easy to use?

Each criterion has 5 question-items. We gave 1 point per item if the answer to the question was YES, 0 points if the answer was NO or CANNOT ANSWER.
Patient engagement in research evaluation tools

Quality Score (0 - 20)
Other tools

- PPI assessment survey (PAS)
  - Satisfaction with engagement
  - 8 items, 3 domains: information, procedural fairness, and quality

- Community engagement in research
  - 32 items, 8 engagement principles

- Patient Engagement Evaluation Tool (PEET)
  - Levels of engagement in the systematic review activities
  - 17 items, 6 meta-criteria of engagement

Soobiah C et al. (2019) *J of Clin Epi* 113
<table>
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<tr>
<td><strong>ABSTRACT</strong> Chari</td>
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<tr>
<th>Project phase</th>
<th>Themes for contributions of engagement</th>
<th>Themes for effects of contributions</th>
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<tbody>
<tr>
<td>Design</td>
<td>Identification or extension of topic, (5) or aims or research questions (5)</td>
<td>Research focus that is meaningful for patients (36)</td>
</tr>
<tr>
<td></td>
<td>Determination of outcomes (65)</td>
<td>Comparators that are acceptable, feasible, or most relevant (4)</td>
</tr>
<tr>
<td></td>
<td>Choice of comparator(s) (5)</td>
<td></td>
</tr>
<tr>
<td>Research design</td>
<td>Practical aspects (for example, setting or timeline) (7)</td>
<td>Address real-world barriers to implementation (6)</td>
</tr>
<tr>
<td></td>
<td>Biased inclusion/exclusion criteria (7)</td>
<td>Alignment with patients’ preferences or practical realities (4)</td>
</tr>
<tr>
<td></td>
<td>Choice of designs, including number/types of arms (8) and participant allocation/randomization (8)</td>
<td>Maximize participation of real-world patients (6)</td>
</tr>
<tr>
<td>Interventions</td>
<td>Adaptation of intervention elements, including delivery (23), materials or tools (14), and topics or content (18)</td>
<td>Less burden for patients or providers (12)</td>
</tr>
<tr>
<td></td>
<td>Training for intervention providers (4)</td>
<td>Alignment with participants’ culture (8) and preferences (2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enhanced intervention usability (14)</td>
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<tr>
<td></td>
<td></td>
<td>Greater adherence to or retention in interventions (6)</td>
</tr>
</tbody>
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- **Acceptability**
- **Feasibility**
- **Rigor**
- **Relevance**
4. When

Is it a good time to administer measurement tools?
When to measure

- Sufficient research project activities
- Sufficient time passed or activities occurred since the last assessment
- Before and after an intervention to enhance engagement
Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research

Marissa Bird BA, BSN, RN, PhD Student | Carley Ouellette MSc, RN, BScN
Carly Whitmore RN, MSch, PhD Student | Lin Li RN, BScN, PhD Student
Kalpana Nair MEd, MSc, PhD, Research Associate | Michael H. McGillivray RN, PhD, Associate Professor
| Jennifer Yost RN, PhD, Associate Professor | Laura Banfield
| Elaine Campbell, Patient Partner | Sandra L. Carroll RN, PhD, Associate Dean

Abstract

Background: Realizing patient partnership in research requires a shift from patient participation in ancillary roles to engagement as contributing members of research teams. While engaging patient partners is often discussed, impact is rarely measured.

Objective: Our primary aim was to conduct a scoping review of the impact of patient partnership on research outcomes. The secondary aim was to describe barriers and facilitators to realizing effective partnerships.

Search Strategy: A comprehensive bibliographic search was undertaken in EBSCO CINAHL, and Embase, MEDLINE and PsycINFO via Ovid. Reference lists of included articles were hand-searched.
“Our findings draw attention to the paucity of research where patient partnership is evaluated quantitatively, as all studies included in this scoping review drew on qualitative techniques, with interviews and focus groups primarily used to evaluate partnership strategies.”

“The evidence base derived from use of these tools is developing and remains in the early stages.”
PEIRS Team

- Alison Hoens
- Annette McKinnon
- Kelly English
- Shanon McQuitty
- Dr. Linda Li
- Dr. Clayon Hamilton
Acknowledgements

• Co-authors
• Recruitment partners
• **About Us Study Team**: Trainees: Bao Chau Tran and Jenny Leese; and PRPs: Lianne Gulka, Sheila Kerr and Wendy Lum

• **Delphi/Pretesting participants**: Fred Cameron, Carolyn Canfield, Richard Cave, Dickie Chad, John Chernesky, Kate Chong, Sandra Dawson, Sarah Fletcher, Douglas Laird, Mary Lee, Joan Levi, Lelainia Lloyd, Kent Cadogan Loftsgard, Alies Maybee, Colleen McGavin, Laurie Proulx, Paige Phillips, Conor Rosen, and Robert Strain, and 3 others
Project Funding

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CIHR Fellowship (2018-2019)
CIHR Travel Award (2018)
CIHR-MSFHR Health System Impact Fellowship (2019-2020)
Thank you!

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@Dr_Clayon
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- Please take a few moments to share your thoughts on today’s webinar. Your comments and suggestions help to improve the resources we offer and to plan future webinars.

- A survey will be launched after the webinar ends and emailed shortly after the webinar.
More resources

- For more information on KT and to explore our resources, visit [www.msfhr.org/our-work/activities/knowledge-translation](http://www.msfhr.org/our-work/activities/knowledge-translation)

- Archived webinar recordings: [www.msfhr.org/ktconnects](http://www.msfhr.org/ktconnects)

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Partnering with Indigenous Communities

Leslie Varley

Friday, May 29th 2020 at Noon