The Meaningful Patient Engagement In Research (PEIR) Framework – an empirically based conceptual framework

Clayon B. Hamilton PhD,1,2 Alison M. Hoen BScPT MSc,1,2,3 Catherine L. Backman PhD,1,2 Annette M. McKinnon,2 Shanon McQuitty,2 Kelly English,2 and Linda C. Li PhD,1,2,3

1University of British Columbia, 2Arthritis Research Canada, 3BC SUPPORT Unit

Background

Patient engagement in research describes patients or their surrogates undertaking roles beyond those of traditional study participants along the continuum of the research process, including knowledge translation. It is being promoted to increase the quality, relevance, and impact of health research, but there is little conceptualization or theoretical development derived from empirical data. The literature provides attributes of patient engagement in research as guiding principles and components of models.1,3 A conceptual framework would link a comprehensive set of concepts to propose what makes patient engagement in research meaningful to patients.

Purpose

To develop a conceptual framework for meaningful patient engagement in research from a patient perspective, with the intended practical value of it being useful to guide the planning, implementing, and evaluating of patient engagement in research.

Methods

Data sources

Transcripts from 1-on-1 in-depth interviews (~1 hr) with 18 patient research partners

Data analysis

The framework development involved three phases:

1. Identification of themes (thematic analysis)4
2. Development of the conceptual framework
3. Confirmation of the conceptual framework using directed content analysis of key literature

This stepwise process allowed us to foreground patient experiences in the emergent conceptual framework, then use the literature to supplement, refute, confirm, and extend the conceptual framework. It was critically reviewed by our entire research team, including four patient research partners, and a final iteration depicted in a figure.

Results

Eight (8) Interconnected Themes

<table>
<thead>
<tr>
<th>Procedural Requirements</th>
<th>Procedural details involved in managing the inclusion of patient partners in a research project to ensure their experiences are rewarding and productive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Convenience</td>
<td>Emphasizes the importance of having a positive and an inclusive organizational/team culture that allows patients to feel comfortable and accepted as equal team members working together</td>
</tr>
<tr>
<td>Contributions</td>
<td>Pertains to the roles and tasks assumed by patients. Patient partners want to contribute their perspectives and experiences to research</td>
</tr>
<tr>
<td>Support</td>
<td>Pertains to the valuable resources, including financial and skills/instructional support offered to patient partners</td>
</tr>
<tr>
<td>Team Interaction</td>
<td>Focuses on aspects of positive research team interaction that are important to patient partners, which involves communication style and rapport</td>
</tr>
<tr>
<td>Research Environment</td>
<td>Focuses on ensuring that patients feel equally important on the research team by demonstrating appropriate recognition and respect</td>
</tr>
</tbody>
</table>

Meaningful patient engagement in research

The planned, supported, and valued involvement of patients in the research process within an interactive team and positive research environment that facilitates effective contributions by patients or their surrogates to help to produce important outcomes while benefitting the patients or their surrogates.

Conclusions

- The PEIR Framework provides guidance on aspects of patient engagement in research to address, for engagement to be meaningful
- It is an orientation on what is important to patient research partners, including deriving benefits and feeling valued
- It can be used to guide teams when planning, implementing, and evaluating strategies for engaging patients in research activities
- It is an essential step in developing an outcome measure for this phenomenon, but is currently provisional and needs further validation

References

2. de Wi WP, et al. Do not forget the professional – the value of the FIRST model for guiding the structural involvement of patients in rheumatoid research. Heal Expect. Aug 2015;18:489-502

Acknowledgement

Dr. Hamilton is a Michael Smith Foundation for Health Research Postdoctoral Fellow in Health Services.
Dr. Li is a Canada Research Chair in Patient-Oriented Knowledge Translation and Harold Robinson/Arthritis Society Chair in Arthritic Diseases.
We thank Tara Azimi (research assistant) and the About Us Study Team - Trainees: Bao Chau Tran and Jenny Leese; and Patient Research Partners: Lianne Guha, Sheila Kerr and Wendy Lum. Thank you to all the participants.