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

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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 models1,2

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

Eighteen purposively-selected key publications from scientific and grey literature covering guiding principles, frameworks, models, and recommendations relevant to engaging patients and the public in research

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.

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 arthritis research. Health Expect. Aug 2015:18:489-502

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Results

Patient Engagement in Research (PEIR) Framework

Procedural Requirements
- Procedural details involved in managing the inclusion of patient partners in a research project to ensure their experiences are rewarding and productive

Convenience
- Emphasizes the importance of choice and accessibility, including sufficient time to engage, and the flexibility to choose how and when to contribute

Contributions
- Pertains to the roles and tasks assumed by patients. Patient partners want to contribute their perspectives and experiences to research

Support
- Pertains to the valuable resources, including financial and skills/instructional support offered to patient partners

Team Interaction
- Focuses on aspects of positive research team interaction that are important to patient partners, which involves communication style and rapport

Research Environment
- 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

Feel Valued
- Focuses on ensuring that patients feel equally important on the research team by demonstrating appropriate recognition and respect

Benefits
- Highlights that it is important to patient partners that they derive benefits from their engagement

Eight (8) Interconnected Themes

1. Aged between 26 and 68 (median 59) years
2. 17 women
3. 14 completed at least a college/university degree
4. Most were retired (n=7) or employed part-time (n=4)
5. 0-10 research projects at Arthritis Research Canada
6. 12 had 1-4 other chronic health conditions or diseases in addition to arthritis.

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