

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 principles¹ and components of models^{2,3}

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

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

1. Kirwan JR, et al. Emerging guidelines for patient engagement in research. *Value Health*. 2016
2. de Wit MP, et al. Do not forget the professional – the value of the FIRST model for guiding the structural involvement of patients in rheumatology research. *Health Expect*. Aug 2015;18:489-503
3. Johnson DS, et al. The patient voice in research – evolution of a role. *Res Involv Engagem*. 2016;2:1-6
4. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. *Qual Res*. 2001;1:385-405

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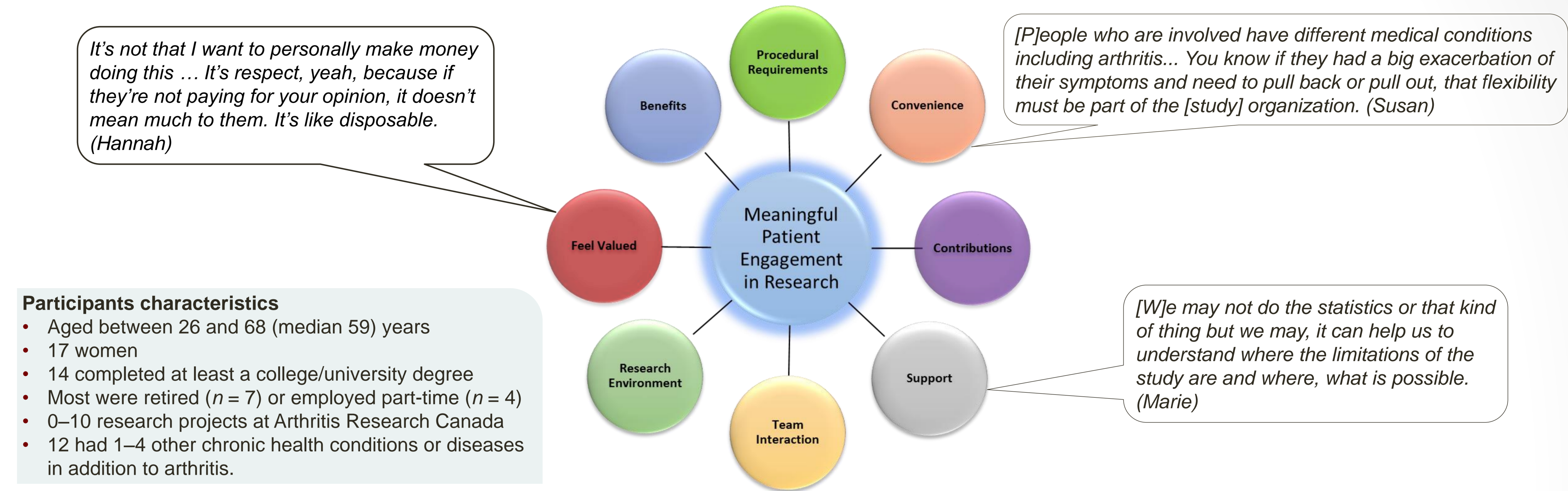
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Results

Patient Engagement In Research (PEIR) Framework



Eight (8) Interconnected Themes

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 of 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

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