

Learning Together: Evaluation Framework for Patient and Public Engagement in Research

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Evaluation of an advisory committee as a model for patient engagement

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Abstract

Patient engagement (PE) is not well defined and little guidance is available to those attempting to employ PE in decision-making relevant to health system improvement. After completing a 2-year PE project, overseen by an Advisory Committee, our objectives were: 1) to evaluate how effectively the project team engaged the Advisory Committee, 2) to examine how Advisory Committee members perceived PE and their role in PE, and 3) to identify barriers and facilitators to PE in order to improve future efforts. Five members of the Advisory Committee completed semi-structured interviews post-project about their experiences. Thematic analysis identified four themes: the approach, participant contributions, participant understanding of PE, and barriers and facilitators to PE. The use of a committee approach was considered beneficial, providing an opportunity to discuss the project in depth, contributing to relationship building, and helping move the project forward. The social aspect of the committee approach was an important part of the engagement process. Participants felt they contributed primarily by participating in discussion, yet could not identify specific contributions they had made. All participants agreed that the experience was meaningful but not profound with regard to how it would impact their engagement, or their engagement of others, in the future. Although experiences were highly subjective, this study suggests that the act of participating in PE has meaning in and of itself to those involved, independent of the activities and/or outcomes of that participation, reflecting a broader public value that PE is an important component of transparent, accountable health systems.

Keywords

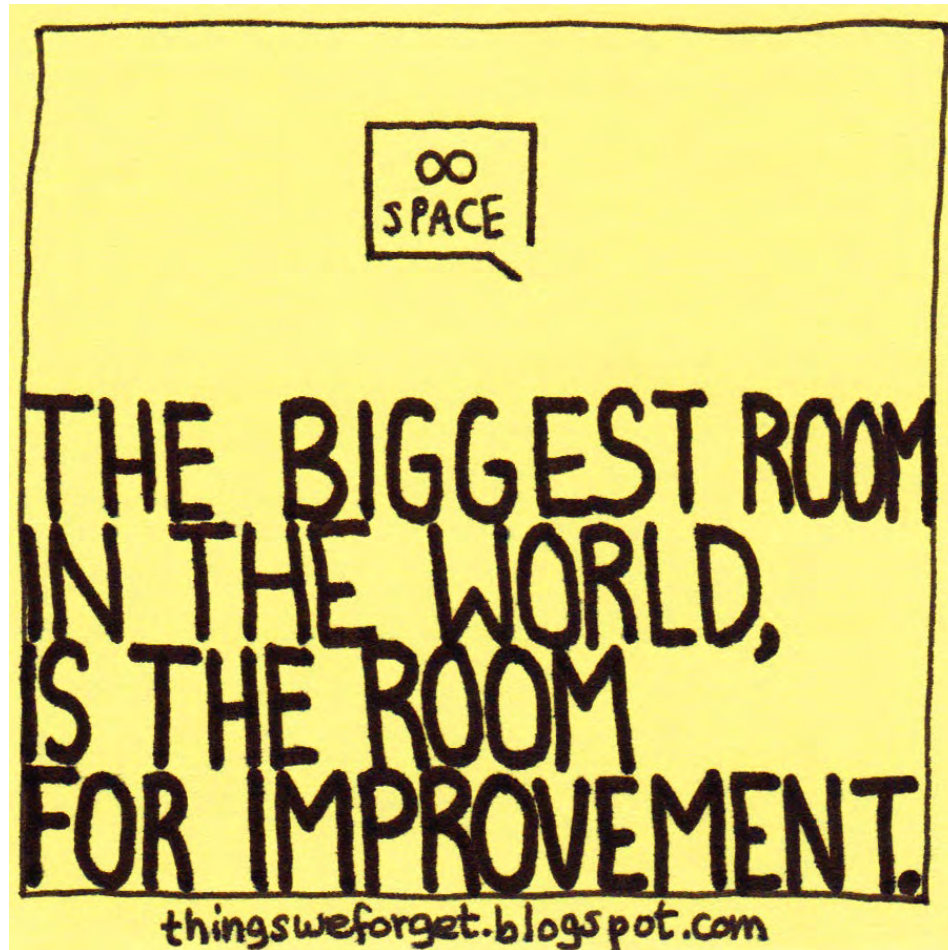
Patient engagement, quality improvement, advisory committee, evaluation

Background

Patient Engagement

In healthcare, patient engagement (PE) is thought to promote accountability and transparency of the health system to the public, create more knowledgeable and empowered individuals, build trust between patients and “the system” (i.e., healthcare providers, administrators, policy-makers, etc.), facilitate understanding of healthcare decisions amongst the public, and improve the ability of the health system to meet patient needs, thereby improving patient outcomes^{1,2,3-7}. Despite seemingly widespread support for engaging patients in health system decision-making, there is little evidence demonstrating the effectiveness of engagement in this context (i.e., of improving services, patient outcomes, or cost-effectiveness)⁸. Part of the difficulty in establishing an evidence base in support of PE may lie in the lack of a common understanding of the concept itself.

PE is often discussed in terms of “citizen engagement,” “community engagement,” or “public involvement”⁹; none of which are consistently defined within the literature⁹. These terms generally refer to a process by which stakeholders (whether patients, citizens, consumers, etc.) are involved in decision-making about public services, programs, or policies^{1,2,10-12}, or perhaps more simply, “a means to involve those who are affected by a decision in the decision-making process”¹³. In practice, PE can take many forms, including focus groups, surveys, one-on-one interviews, one-time meetings/workshops, citizen juries, committees, and advisory groups^{2,10,13}. Given the potential involvement of various stakeholder groups and the many models of engagement to choose from, the concept of PE itself remains broad and its practical aspects are not well understood^{1,6,8,9,14-18}. After conducting an extensive review of the literature as well as interviews and focus groups with stakeholders, Gallivan et al⁹ defined PE as “a relative term subjectively defined by individuals or groups/organizations that are planning to actively involve



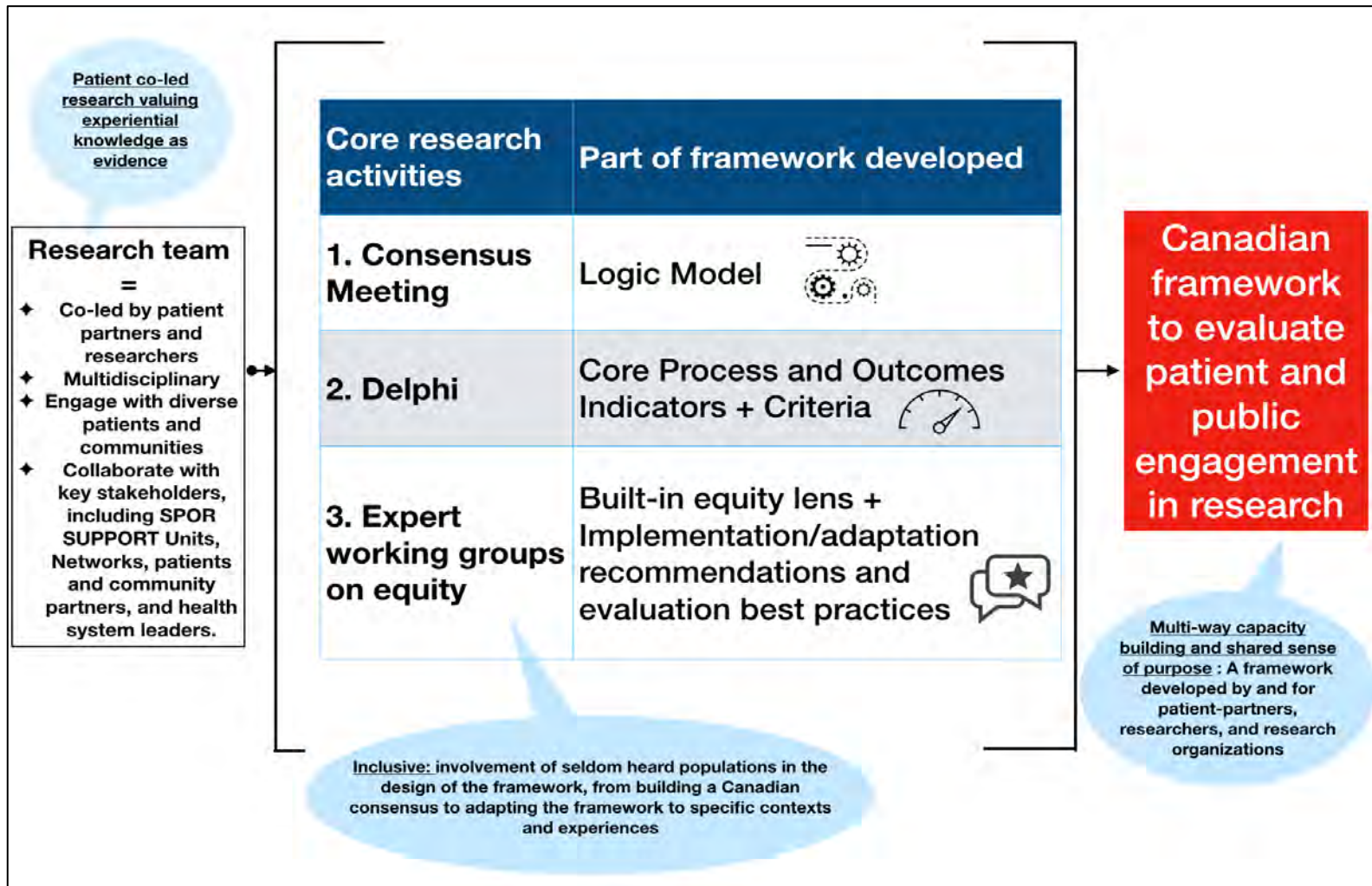
We set out to build

A PPE evaluation framework that provides a **common minimal structure** around which the research community can build their own evaluation initiatives, yet promotes comparability across evaluations and allows for flexibility and adaptation to different populations and contexts



We took a [co-design approach](#) with patient and community partners, engagement practitioners, researchers, & health system leaders



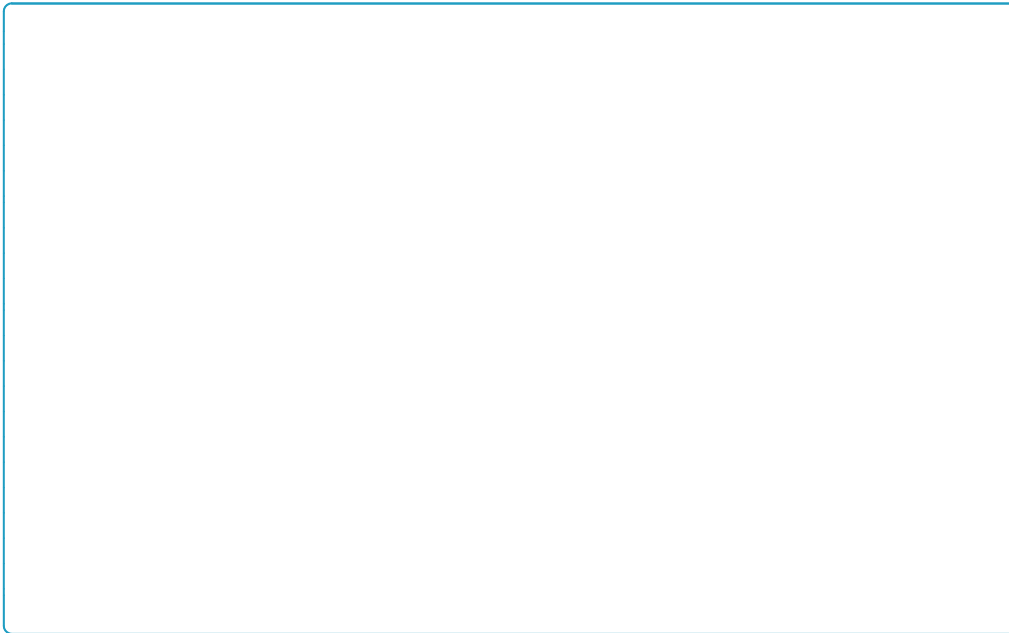


1. General recommendations for adaptation and implementation
2. Engagement with Indigenous communities
3. Engagement with caregivers
4. Engagement with immigrant and newcomer communities
5. Engagement with persons with physical and/or intellectual challenges/disabilities
6. Engagement with persons with low literacy levels



PROTOCOL

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★ GUIDING PRINCIPLES

- RELATIONSHIP BUILDING
- CO-BUILDING
- EQUITY, DIVERSITY & INCLUSION
- SUPPORT & BARRIER REMOVAL
- TRANSPARENCY
- SUSTAINABILITY
- TRANSFORMATION

CLICK HEADINGS
FOR MORE INFO

- ★ = MUST HAVE
- + = NICE TO HAVE

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ROLES

- ★ Understanding the part of the research project one is involved in
- ★ Understanding the project potential effects on the patients and/or community
- ★ Shared understanding among partners of the goals, roles, responsibilities and expectations
- ★ Defining together the goals, roles, responsibilities and expectations
- ✚ Clarity of the terms of reference
- ✚ Existence of a terms of reference
- ✚ Understanding of the full research project

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RECOGNIZING

- ★ Valuing patient expertise and lived experience
- ★ Acknowledging and showcasing what has been learned from research partnership
- ★ Acknowledging and showcasing patient partners' contributions
- ✚ Expressing gratitude to all patient partners
- ✚ Providing feedback to patient partners at each stage of research as an acknowledgement of their contributions
- ✚ Being co-authors on publications

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COMMUNICATING X

- ★ Communicating in an easy-to-understand way
- ★ Offering feedback about the project as it unfolds
- ★ Communicating openly and frankly
- ⊕ Having access to working documents (protocol, meeting minutes, reports, etc.)
- ⊕ Offering feedback about the project at the very end
- ⊕ Determining the mode of communication (speech, writing) according to patient partner preferences

★ **GUIDING PRINCIPLES** ▶

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- TRANSFORMING CARE** X
- ★ Patient experience
 - ★ Quality of care
 - ★ Patient safety
 - + Health equity
 - + Quality of life
 - + Services for patients and families
 - + Patient journey
 - + Health system
 - + Healthcare provider ability to guide the patient
 - + Healthcare provider knowledge

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Centre of Excellence on Partnership with Patients and the Public (CEPPP)

<https://ceppp.ca/en/resources/learning-together-evaluation-framework-for-patient-and-public-engagement-ppe-in-research/>

Questions, comments?

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