

Development of the Participatory Research to Action Framework (PR2A)

As patients, caregivers, and other knowledge users are increasingly involved in health services research, we identified the need for a framework to guide authentic engagement of experts-by-experience. The framework needed to be flexible enough to accommodate a wide range of research contexts and methods – but structured enough to address the full continuum of applied health services research including implementation and evaluation. We describe three cases representing stages in the development and application of the PR2A.

“PR2A helps researchers to navigate the uncertainties of participatory work with clear steps for iterative project development and relationship-building with end-user experts-by-experience. With its track record of successful application, PR2A is of interest to anyone committed to rigorous, meaningful and action-oriented health services research.”



- Dr. Justine Giosa, Executive Director and Scientific Director, SE Research Centre

Project Overview

Participation of experts-by-experience has been shown to improve the relevance and quality of research.¹ One approach to patient participation is **experience-based co-design**, which uses observation, video prompts, and workshops to explore and respond to health services issues.² Another approach is **integrated knowledge translation**, which involves knowledge users like clinicians and policymakers, with the goal of closing gaps between research knowledge, and its uptake in practice and policy.³ A third approach is **service design**, which engages people in open-ended creative processes.⁴

However, the SE Research Centre team found that individually, none of these approaches fully addressed the needs of both researchers and experts-by-experience engaged in their studies.

What did we do?

The SE Research Centre team iteratively applied and blended the three participatory research approaches (experience-based codesign, integrated knowledge

translation and service design) across three cases.

This led to the development of a new, action oriented approach called the **Participatory Research to Action Framework (PR2A)**.⁵

What did we find?

Case 1— Identifying the need for a new framework through a cardiac surgery pathway project: in 2017, the SE Research Centre was engaged by a large teaching hospital to help improve a coordinated care pathway for cardiac surgery patients. The researchers had previously used experience-based co-design and integrated knowledge translation methods and found them too prescriptive to fluidly engage with experts-by-experience as authentic research partners throughout. They decided to use a service design approach instead. Service design uses “generative methods,” which explore not only what people say and do, but also what they make when encouraged to participate creatively. The process led to the successful design of an ecosystem of supports for cardiac patients and their unpaid caregivers. However, the team encountered several challenges.

First, service design approaches are intentionally unstructured at the start, to maximize creativity. This was difficult to balance with the need for transparent, structured, and stepwise research protocols. Second, while service design methods offered guidance for ideating and prototyping interventions or tools, they did not offer guidance for implementation or evaluation. Thus, the proposed ecosystem of supports was never fully put into practice or evaluated.

Case 2 – Developing the PR2A through process mapping: through reflection on experiences including the project described above, the SE Research Centre team decided to formally develop a tailor-made approach to participatory research, customized to applied health services research and evaluation studies. Workshop sessions were held to identify concepts and strategies from relevant bodies of literature. Next, these concepts and strategies were mapped onto the complete cycle of research, from study conception to implementation and evaluation. These findings were synthesized into a framework that addressed how participation could be embedded in six stages of a research cycle (Figure 1), offering guidance for who, when, how to involve participants in each stage. In doing so, the PR2A balances the generative potential of creativity with the rigor of a structured research process.

Case 3 – Applying the PR2A in a dementia care project: the PR2A has since been applied in several projects. One early example was a project to explore and respond to the experiences of family caregivers and care providers of persons living with dementia,

initiated in 2018. The project begun with a *readiness* assessment, where a group of family caregivers approached the SE Research Centre and raised a need for a dementia focus. Following, the *discover* stage included literature reviews, environmental scans, and diaries and photos produced by caregivers. Qualitative analysis of these materials was used to *define* the problems faced by caregivers. Co-design workshops with caregivers and care providers were used to *develop* a prototype for a paper-based tool that could help caregivers and care providers to collaboratively navigate the dementia journey. *Delivery* and *measurement* lead to iteration and expansion into both an analogue and a digital tool. This tool is now available in culturally adapted and multilingual versions.

What are the next steps?

The next steps include publishing these cases to support the dissemination and use of the PR2A.

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Figure 1. Participatory Research to Action Framework (PR2A)

