

# Developing the Participatory Research to Action (PR2A) framework

As patients, caregivers, and other knowledge users are increasingly involved in health services research, we identified the need for a framework to guide involvement of experts-by-experience. The framework needed to be flexible enough to encompass a range of contexts and methodologies— but structured enough to embed involvement of experts-by-experience across the complete continuum of applied health services research, from identifying a problem to disseminating and evaluating solutions.

The Participatory Research to Action (PR2A) framework brings together concepts from service design, co-design, and integrated knowledge translation to articulate a six-stage process for participatory applied health services research. We describe three cases representing stages in the development of the PR2A framework: a stroke care project that highlighted gaps in off-the-shelf approaches to involving experts-by-experience; the participatory development of the PR2A framework itself; and the successful application of the new framework in a study with caregivers of persons living with dementia.

## Project Overview

Patients, caregivers, and other experts-by-experience are increasingly recognized as important partners in health research. Participation of experts-by-experience has been shown to improve the relevance and quality of research.<sup>1</sup>

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.<sup>2</sup>

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.<sup>3</sup>

However, researchers at the SE Research Centre found that these approaches did not fully meet the needs of both researchers and experts-by-experience engaged in their studies. The range of methods used was too limited, often relying on traditional interview- and focus group-based

approaches, and decision-making still lay largely with researchers rather than experts-by-experience.

To address these perceived challenges, the SE Research Centre team introduced an additional approach: **service design**, which engages people in open-ended creative processes.<sup>4</sup> The team then drew on these three approaches— experience-based co-design, integrated knowledge translation, and service design— in the development of a new, action-oriented framework that balanced creativity and structure.

## What did we do?

We use 3 cases to describe the development of the **Participatory Research to Action (PR2A) framework**<sup>5</sup>:

### Case 1: Identifying the need for a new framework

In 2017, the SE Research Centre was engaged by a large teaching hospital to help improve a coordinated care pathway for cardiac surgery

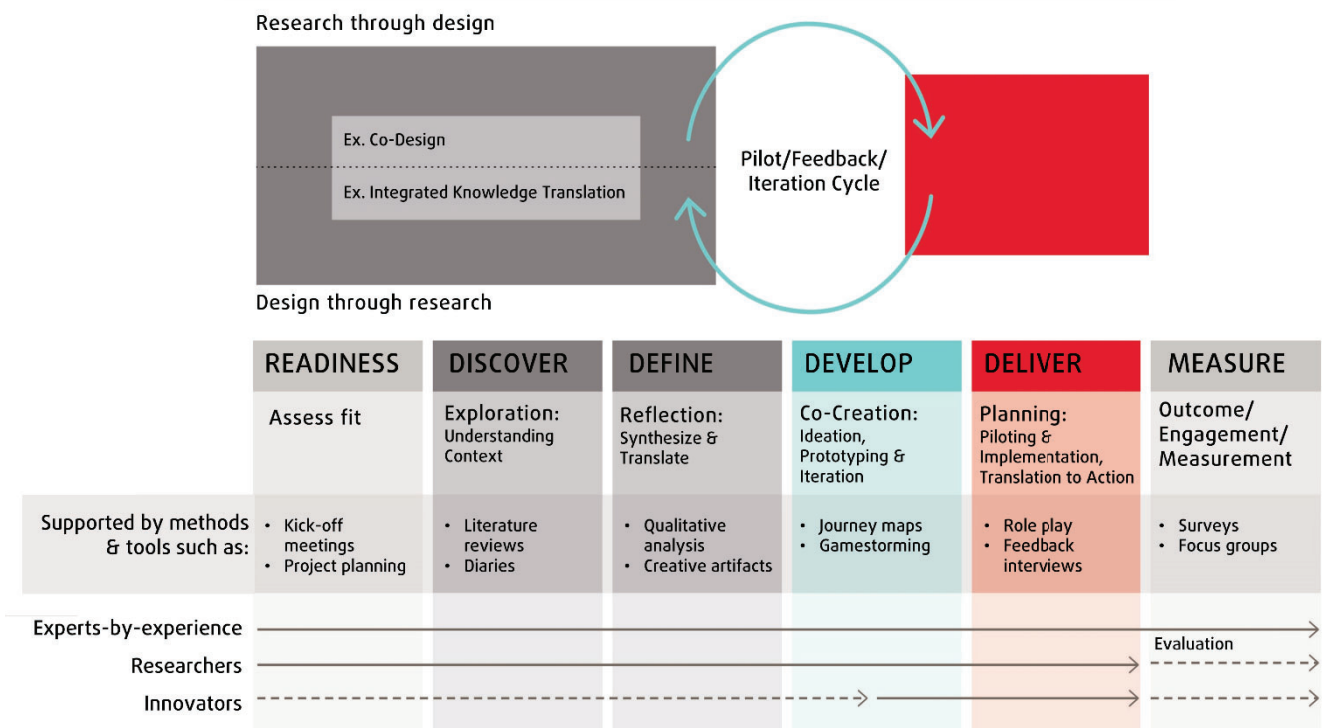
patients. The researchers had previously used experience-based co-design and integrated knowledge translation methods and found them too prescriptive to fluidly engage with experts-by-experience as authentic research partners throughout. They decided to use a service design approach instead. Service 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 on and prototyping interventions or tools, they did not offer guidance for implementing or evaluating these. The proposed ecosystem of supports was never fully put into practice or evaluated.

## Case 2: Developing a new framework

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: *assess readiness, discover, define, develop, deliver, and measure* (Figure 1). This framework offers guidance for who to involve, when to involve them, and how to involve them in each of these stages. In doing so, the framework balances the generative potential of creativity with the rigor of a structured research process.

**Figure 1. Participatory Research to Action (PR2A) framework**



### Case 3: Applying the new framework

The PR2A framework has since been applied in several projects. One early example was a project to explore and respond to the experiences of unpaid caregivers of persons living with dementia, initiated in 2018. Following the *readiness* assessment, the *discovery* phase 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 was the impact?

The PR2A framework has been applied successfully in a wide range of SE Research Centre projects. For example, the team:

- developed and evaluated a training package for social care workers to support persons experiencing homelessness through the end of life;
- is co-designing and testing an approach to promote mental health conversations between home and community care providers and older adults during routine care interactions; and
- has co-created a model of long-term life care at home to match the needs and preferences of aging Canadians.

The balance of flexibility and structure within the PR2A framework has influenced the culture of the SE Research Centre, building capacity for managing the uncertainty of participatory work— such as the need for iterative protocol development and sustainable relationship building with experts-by-experience. Given its track record of successful application, this framework will be of interest to other researchers seeking to engage in participatory, applied health services research.

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