Research Centre

Developing the Participatory Research to Action (PR2A) framework

Patients, caregivers, and other knowledge users are increasingly involved in health services research. The SE Research Centre team 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 across the complete continuum of applied health services research, from identifying a problem to disseminating and evaluating solutions.

The Participatory Research to Action 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 people 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 argued 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). Meanwhile, integrated knowledge translation involves knowledge users like clinicians and policymakers, with the goal of closing gaps between research knowledge, and its uptake in practice and policy(3).

However, researchers at the SE Research Centre found that these approaches did not fully meet the needs of 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 this, the SE Research Centre team first brought in the additional approach of service design, which engages people in open-ended creative processes(4).

The team then drew on these three approaches when developing a new, action-oriented framework that balanced creativity and structure.

What did we do?

We use three cases to describe the development of the PR2A framework. First, we describe a project prior to the formal development of the PR2A framework, in which the SE Research Centre team members encountered limitations of approaches described in the literature at the time. Next, we describe the participatory development of the PR2A framework itself. Finally, we describe an early example of the framework's application.

What did we find?

Case 1: Identifying the need for a new framework

In 2017, the SE Research Centre was engaged by Trillium Health Partners 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 step-wise research protocols. Second, while service design methods offered guidance for ideating on and prototyping interventions or tools, it did not offer guidance for implementing or evaluating these. Partly because of this limitation, 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* (see Figure 1, below). This framework offered 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.

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 caregivers of people with dementia, initiated in 2019 in collaboration with the Alzheimer's Society of Canada. Following *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 facing caregivers. Co-design workshops with caregivers and staff were used to *develop* a prototype for a paper-based tool that could help caregivers and staff to collaboratively navigate the dementia journey. *Delivery* and *measurement* lead to iteration and expansion into both a web-based and 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 is co-designing and testing an approach to have conversations about mental health between home and community care providers and older adults during routine care interactions; developing and evaluating a training package for social care workers to support persons experiencing homelessness through the end of life; and proposing a model of long-term life care at home that can meet the health and social care needs 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.

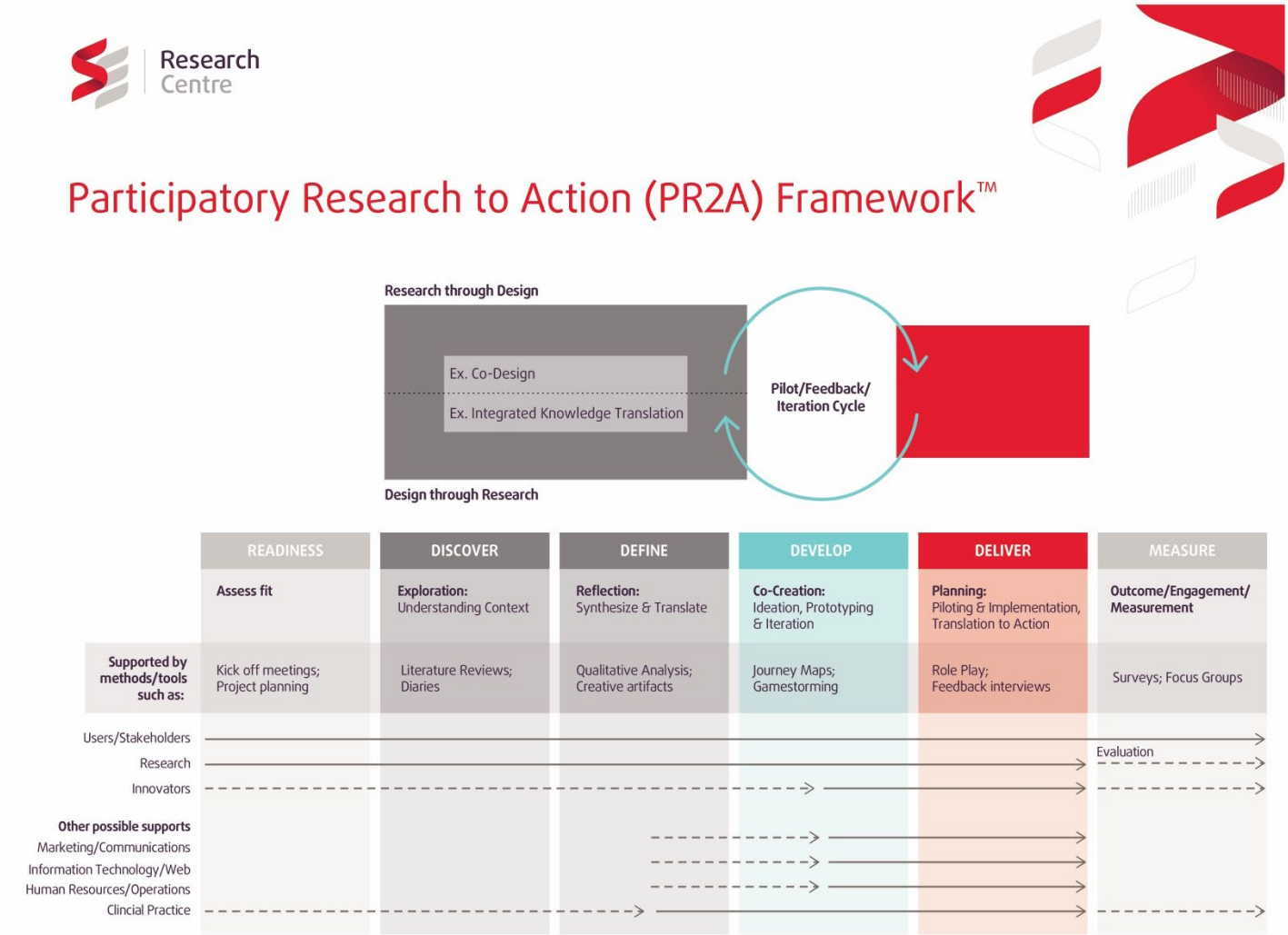

Figure 1. Participatory Research to Action framework

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About the SE Research Centre

The SE Research Centre is funded by SE Health to conduct impact-oriented health services research and evaluation for the benefit of Canadians. We study the needs of people, their caregivers, and health care providers, to develop evidence-based solutions to tough health and social care problems. Our researchers collaborate with a wide variety of community and academic partners across Canada.

In the SE Research Centre there are four fields of research and evaluation: Aging in Society; Dying, Death and Grief; Health and Care Experiences; and Models of Care Delivery.

SE Research Centre. Creating a brighter future of health.

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