

# Impact of patient partner co-design on survey development in primary care research

## Case study

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Canada's Strategy for Patient-Oriented Research—a national coalition of several institutions and organizations across Canada—emphasizes the importance of patients, researchers, health care providers, and decision makers working collaboratively to improve the health of Canadians.<sup>1</sup> Patient engagement is a central component of patient-oriented research, as it integrates the perspectives of people with lived experience into health research, thereby helping to create outcomes that are meaningful to the community.<sup>1,2</sup>

In the course of our research examining the spread and scale of electronic consultation (eConsult) services, we have created governance structures that fully integrate patient partners at every level. Patients are members of the eConsult Steering Committee and all other project committees and working groups. Our experience has demonstrated that engaging patient partners as full team members has led to projects being influenced in meaningful ways at each stage of the process, potentially leading to more relevant findings that influence policy makers and program development.

In this article, we examine our process of engaging patients in a large-scale research and implementation project, focusing on one element—design and circulation of a needs assessment survey—as an example of our broader strategy.

### Expanding e-consultation for chronic pain

The Web-based tool eConsultBASE™ is a secure platform that enables primary care providers (family physicians or nurse practitioners) to have timely access to specialist advice for patients. In 2018 we received funding to expand the service to improve patient access to chronic pain expertise in 4 provinces. We assembled a collaborative, solution-focused, multidisciplinary team of patient partners, researchers, clinicians, and decision makers. Five patient partners have been involved at every level of the research process, including as knowledge users on the grant application development and submission, and as members of the executive or steering committees or both.

The first phase of the project was to conduct a needs assessment survey of individuals who were accessing a chronic pain specialist for the first time, in order to assess the wait times they experienced and inform the development of an effective e-consultation service in

each province. Our team developed the survey through a co-design process, engaging all health care stakeholders, including patients and caregivers, across all stages of the research.<sup>3,4</sup> The process included several interactive meetings and e-mail discussions among clinicians, researchers, and patient partners. These meetings were facilitated to ensure that everyone had an equal chance to contribute. Additionally, one meeting was held with the project lead and patient partners. Discussion prompts were used to structure the conversations. One patient partner from each participating province contributed feedback to ensure that the survey was responsive to the needs of people living with chronic pain and sensitive to local community contexts, norms, and cultures.

Co-design was achieved by providing education opportunities, using inclusive language, having proper meeting facilitation, and including multiple patient partners on every project committee. Data collection is currently under way, and patient partners involved in the study design will participate in the analysis of the data and manuscript development.

### Value of co-design

Our team began with a first survey draft derived from past needs assessment surveys created for similar projects using a co-design approach.<sup>5</sup> Three significant changes were made to increase accessibility: our team changed, modified, or excluded questions that patient partners advised might cause stress for individuals or mistrust of the research team; dissemination of the survey was expanded to provide multiple ways to complete it, either from the waiting room or at home; and the survey was shortened to reduce the burden of completion.

**Questions.** The wording and inclusion of questions were changed. For example, a question regarding occupation was revised to avoid disempowering those unable to work because of their chronic pain symptoms. Additionally, patient partners raised concerns about why it was necessary to collect income information. Patient partners explained that questions like these are perceived as unnecessary and intrusive, resulting in patients mistrusting the intent of the research.

**Dissemination.** The dissemination of the survey was altered to better meet the needs of the community.

Patient partners raised concerns about dissemination via medical appointments, because the experience of a medical appointment can cause considerable stress, pain, and fatigue. For this reason, more ways to complete the survey were added. Specifically, we added options allowing the use of a tablet computer, pen and paper, or a research team member's assistance. Furthermore, individuals could complete the survey using any of these options either in the clinic or later from home. This type of flexible work flow had not been employed in previous patient surveys conducted by our team.

**Length.** Reducing the survey length to minimize burden was achieved by removing demographic questions that were not necessary to meet our research objectives but that are commonly included in patient surveys, such as education level. We also condensed some survey questions into single questions. Shortening the survey might increase the ability and willingness of individuals to participate and complete the survey.

While greatly beneficial, co-design can be challenging to implement effectively. Care must be taken to ensure patients feel truly engaged and comfortable expressing their views. Providing safe spaces for learning, such as individual meetings or separate patient partner meetings in advance of larger team meetings, can improve participation. Proper meeting facilitation can reduce anxiety among patient partners.<sup>6</sup>

## Conclusion

Through the process of co-design, we were able to change the survey to better meet participants' needs by increasing the accessibility to and acceptability of the survey. Our team has fully adopted a co-design approach into all activities of the project from survey design to knowledge dissemination. We have provided 3 simple tips for how other research teams can adopt a similar approach to patient engagement (**Box 1**). We encourage other researchers to challenge themselves and fully integrate co-design approaches to ensure patients' needs and perspectives are represented and well integrated into research.

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### Box 1. Steps to engaging patient partners

The following steps help patient partners to feel engaged and comfortable expressing their views.

- Create an open environment in which everyone, including patient partners, can contribute feedback:
  - circulate discussion prompts before a meeting to allow people to prepare their thoughts and
  - have a meeting facilitator.
- Integrate patient partners in the governance structure by inviting them to be members of different committees, such as executive committees and working groups.
- Use a co-design approach when developing grant applications, research, and knowledge dissemination materials by engaging all stakeholders, including patient partners, as equal partners. A list of resources on co-design is available from **CFPlus**.\*

\*The list of resources on co-design is available at <https://www.cfp.ca>. Go to the full text of the article online and click on the **CFPlus** tab.

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#### Acknowledgment

Funding for this project was provided by the Canadian Institutes of Health Research. The funder had no role in the development of the survey or the preparation of the manuscript.

#### Competing interests

None declared

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*Can Fam Physician* 2022;68:235-6. DOI: 10.46747/cfp.6803235

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