

Brief Report

Discussing Around a Virtual fire: Citizen Engagement in a Shared Decision-Making Conference

Short title: Shared Decision-Making Conference

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Keywords (based on MeSh 2021)

Decision-Making; Education; Patient Care Team; Congresses as topic; Patient participation; Stakeholder Participation

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Brief Report

Discussing Around a Virtual fire: Citizen Engagement in a Shared Decision-Making Conference

Abstract

An online conference was organized to promote the Interprofessional Share Decision-Making model and maximize its dissemination among stakeholders (citizens, health care providers, administrative staffs, policy makers, academics) in Canada. The goal was to enhance knowledge and engagement to share decision-making in a patient-oriented approach since shared decision-making hampered by reduced face-to-face contact, fear of infection and overworked health professionals due to the COVID-19 pandemic. Therefore, we share a summary of what has been done to engage citizens on shared making and to feed the interprofessional community on active citizen engagement in online conference.

Keywords

Decision-Making; Education; Patient Care Team; Congresses as topic; Patient participation; Stakeholder Participation

Key points

- The engagement of patient-partners and citizens is an added value for the organizers of this online scientific event.
- Engagement of patient-partners and citizens should remain meaningful for a good partnership to develop and to take full advantage of their valuable contributions.

- Two strategies were used to interest participants in SDM during the virtual conference: evoke their personal experience of SDM – or lack of it – using a live survey and discussion around SDM in breakout rooms.

Background

Active citizen or patient engagement in health and social services contributes to improving health and social services education, organization and governance, research and direct care (Carman et al., 2013). It is an inherent part of the interprofessional approach to care, which includes joint participation of citizens and patients in decision-making and action planning (Légaré et al., 2011). However, there is limited knowledge about involving citizens or patients in organizing online scientific conferences (Carman et al., 2013; Domecq et al., 2014). In fact, it is not included as such in any model of patient centered care, engagement or patient oriented research (Canadian Institutes of Health Research, 2014; Carman et al., 2013; Pomey et al., 2015).

Population health and the quality of care and services provided by the health and social services could be improved with patient engagement at different levels of the health system (Carman et al., 2013; Pomey et al., 2015). This can be achieved by patient-centered health care and patient oriented research (Sacristán, 2013). Patient oriented research or POR refers to a continuum of research that engages patients or citizens as partners, focusses on patient-identified priorities and improves patient outcomes (Canadian Institutes of Health Research, 2014). This engagement provides valuable research contributions to acceptability, feasibility, rigor, and relevance through better alignment with patients' and clinicians' real context and preferences (Bird et al., 2020; Forsythe et al., 2019). Active

patient engagement in health and social services education contributes in many ways to the future professional's interpersonal skills development (e.g., empathy, communication, teamwork). Scientific conferences are a well-known and widely used means of continuing education and patient oriented research is a comprehensive way to educate health professionals about shared-decision making (SDM) because different stakeholders are involved. Professionals are then more responsive to the population's needs and their practice is more sustainable (Towle et al., 2010), resulting in more SDM and more informed choices (Barr et al., 2020; Légaré & Witteman, 2013). Therefore, we describe our experience of holding a virtual conference on interprofessional shared decision-making (SDM) that involved citizens and patients, and how we achieved active participation of the general public as well as the interprofessional community.

Methods

Context and organization of the virtual conference

As members of a large research center, we held an online event that aimed to raise awareness in the community (both in health and social services and the general public) about interprofessional shared-decision making (Interprofessional-SDM). Interprofessional-SDM refers to diverse professionals as well as patients making decisions together based on the best available evidence, professionals' experience and patients' values and preferences (Dogba et al., 2016; Elwyn et al., 2000). The conference involved citizens from A to Z (organization to this publication) (CIUSSS-CN & VITAM, 2021). The event consisted of two hours one evening and three more the next morning, held on the virtual platform *Zoom*. It took place in February 2021 in Quebec City (Canada), almost one

year into the Covid-19 pandemic. The evening time slot was chosen to reach more citizens and day workers who cannot afford to attend a conference during usual working hours. Various stakeholders (e.g., patient-partners, citizens, students, researchers, professors, administrators, health and social services professionals) were involved in its organization as scientific and organizational committee members or as guest speakers and moderators. Event organization lasted 5 months and at least a dozen virtual meetings took place in addition to subcommittee meetings (e.g., detailed event planning, design of event website, invitations, planning speeches and scenarios, organizing a scientific dissemination competition and assuring conference visibility). The goal of this event was to inform the public and health and social services personnel about interprofessional-SDM from different perspectives, including ethical, research, education, and ethnocultural, and its relevance to patient-partners, citizens and health and social services administrators. The first part of the event included: 1) theoretical content; 2) video to demonstrate SDM in care; 3) live survey; and 4) a panel discussion including patient-partners and questions from the public. The second part included 1) a presentation from patient-partners who shared about their involvement in SDM research with a SDM methodology expert; 2) an active break with a kinesiologist; 3) an integration activity (see below); and 4) a discussion panel with speakers (i.e. health and social services providers, researcher and professor) on SDM and about strategies to engage people to practice SDM. Time was also planned at the end of each program component to answer questions from the public. In addition, there was a short presentation about the scientific dissemination competition and an awards distribution, with the goal of raising awareness about the research center among the public. During the

entire conference, knowledge was shared within a spirit of patient-oriented research (Canadian Institutes of Health Research, 2014).

We wished to involve the general public in a genuine and meaningful way in the design and evaluation of our projects, as patient partners have often reported that their participation in such events was tokenistic. This engagement at all stages, although not a strategy *per se*, was perhaps the most powerful incitement to engagement. The organizational and scientific committee included two citizens, who proposed a conference format to reach the general public. They participated in choosing the topic, developing learning objectives and designing the program. They were also jury members, with researchers and center employees, for the scientific dissemination competition in which researchers explained the general scope of their project in a short text destined for the general public. A public vote was then held to select projects to be highlighted at the conference. Three other patient-partners and citizens were involved as guest speakers and moderators for the panel discussions. They shared their SDM experience and perspectives which created a conversational spirit between the panel and the audience. After the conference, patient-partners (IC and GP) were involved actively in the writing of this report.

Participant characteristics

The event brought together 218 persons interested in learning more about SDM. On the event's registration form, almost one third of the participants (29%) self-identified as members of the general public, i.e. as retirees, workers (non-academic or not from health

sectors) or taxpayers. In addition, there were 39% of participants from academia (i.e. researchers, research professionals, professors and students), 13% were administrators and 19% were health care professionals (i.e. physicians, physiotherapists, podiatrists, psychologists, nurses, social workers, occupational therapists). All regions of the province of Quebec were represented and 5% of the participants were from outside the province of Quebec. We did not collect demographic data on participants because it was not intended as a research project. However, people consented to be recorded and were free to contribute to the live survey. We obtained an ethics exemption from the committee affiliated to our institution.

Table 1*Questions for the live survey*

In the past year, when you have received care or treatment from a health care professional (e.g., from a physician or a nurse), how often ...

1. Were the treatment or care choices discussed?
2. Were the advantages and disadvantages about the different choices presented?
3. Were you asked about your preference/opinion?
4. Were you asked about your preferred option?
5. Were you as involved as you wanted to be in the decision about your treatment and care?

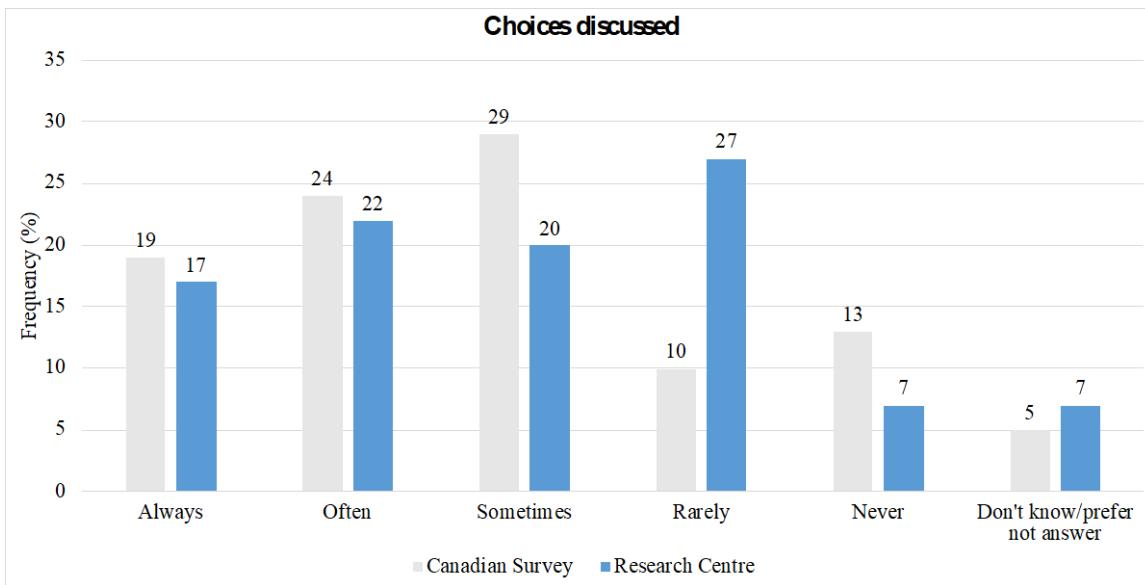
Citizen engagement in shared-decision making

The main priority of the scientific committee was to create active public participation during the conference beyond the question periods. Our first strategy to interest participants in SDM was to evoke their personal experience of SDM – or lack of it – using a live survey. We extracted five questions (Table 1) from a 2017 pan-Canadian survey of 1010 Canadians' experience of SDM (from all provinces including Quebec) (Haesebaert et al., 2019).

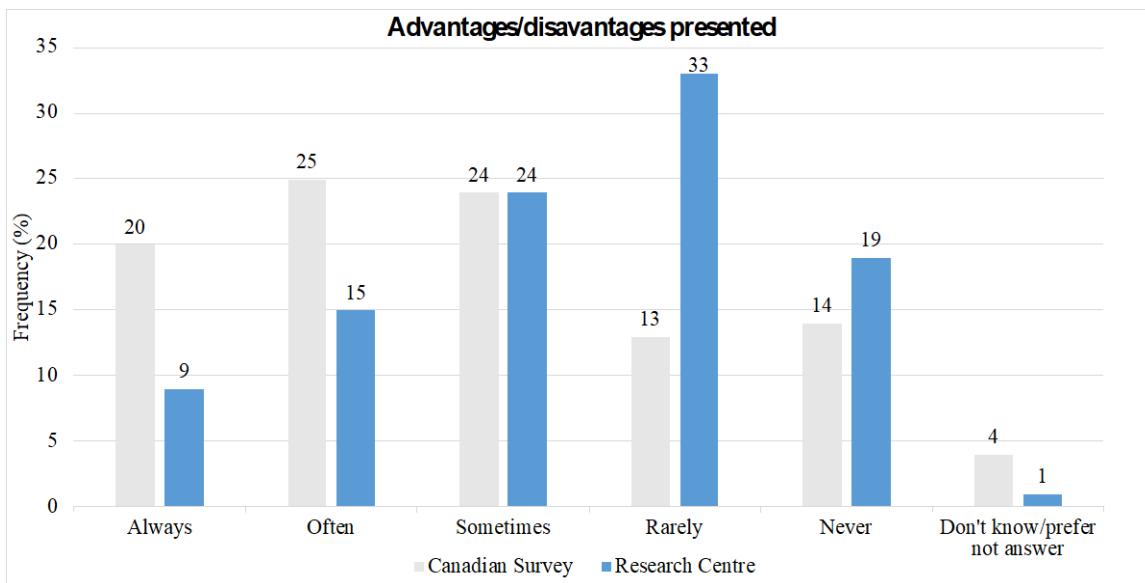
Using the live survey option from the virtual platform, 86 participants volunteered to take the survey. Each question had six answer options (i.e. always, often, sometimes, rarely, never and I don't know/prefer not to answer). To give them a comparison for discussion, we displayed their responses beside responses to the 2017 survey, in real time, after each question (Figure 1) The 2017 results suggested that Canadians were not very engaged in decisions about their health. The evening discussion panel discussed these live survey results and the comparison with the 2017 Canada-wide results.

The second strategy to interest participants in SDM was to ask for their answers to two fundamental questions written by the citizens on the scientific committee: “What do stakeholders need to change to implement SDM?” and “How could SDM improve people’s health?”. Participants were split into virtual breakout rooms (4 to 6 participants per room) for 15 minutes. One person from each room was responsible for reporting back the participant’s reflection on the instant discussion (chat) available for all the audience. This was not orally presented due to a lack of time in the schedule.

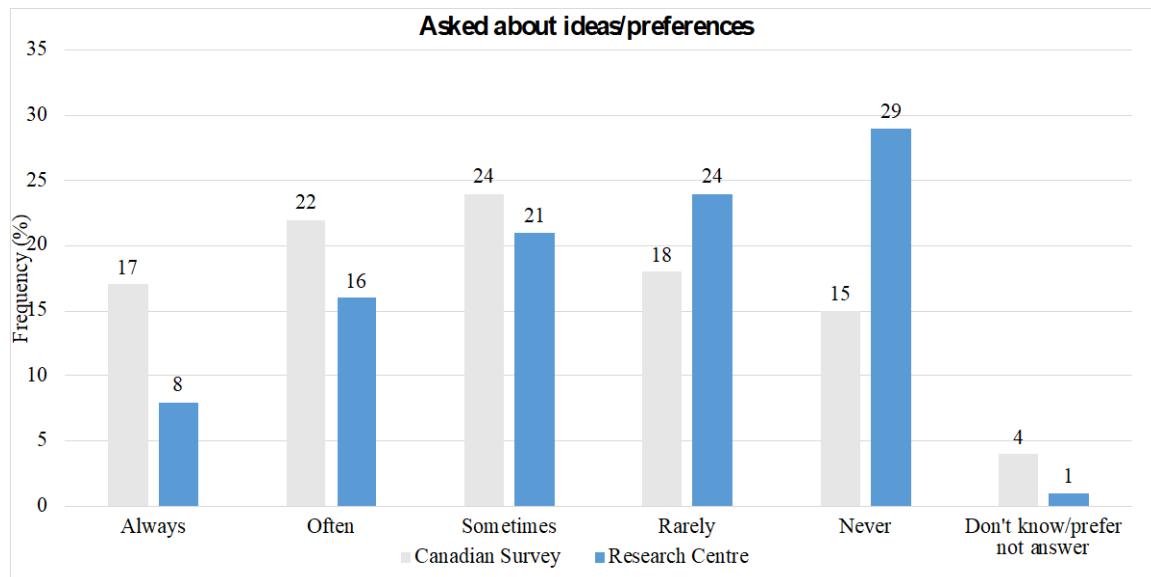
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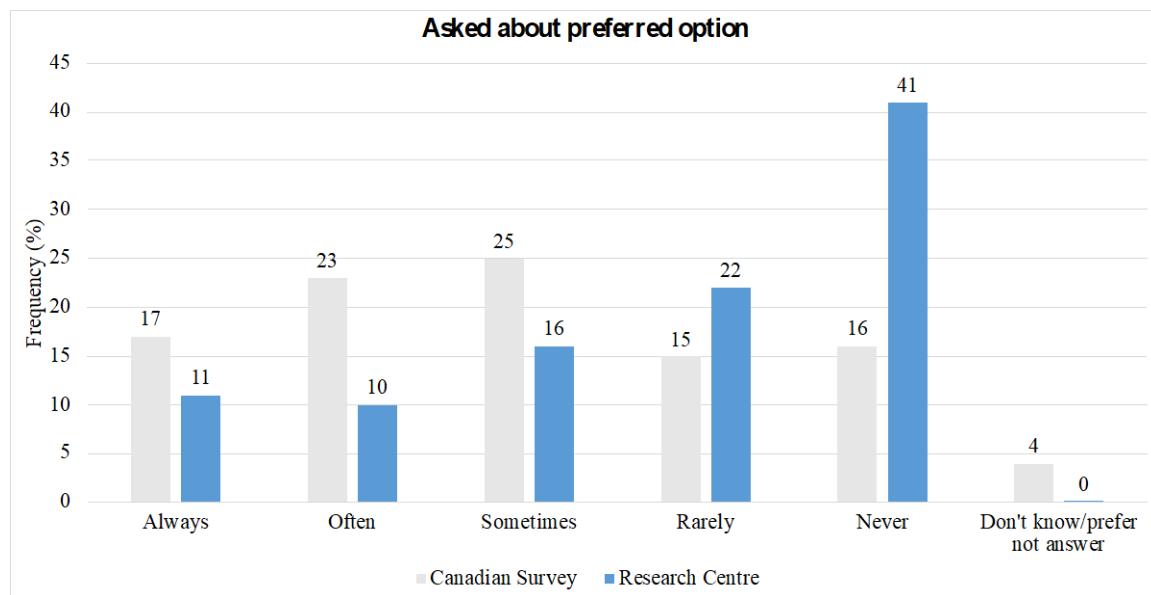
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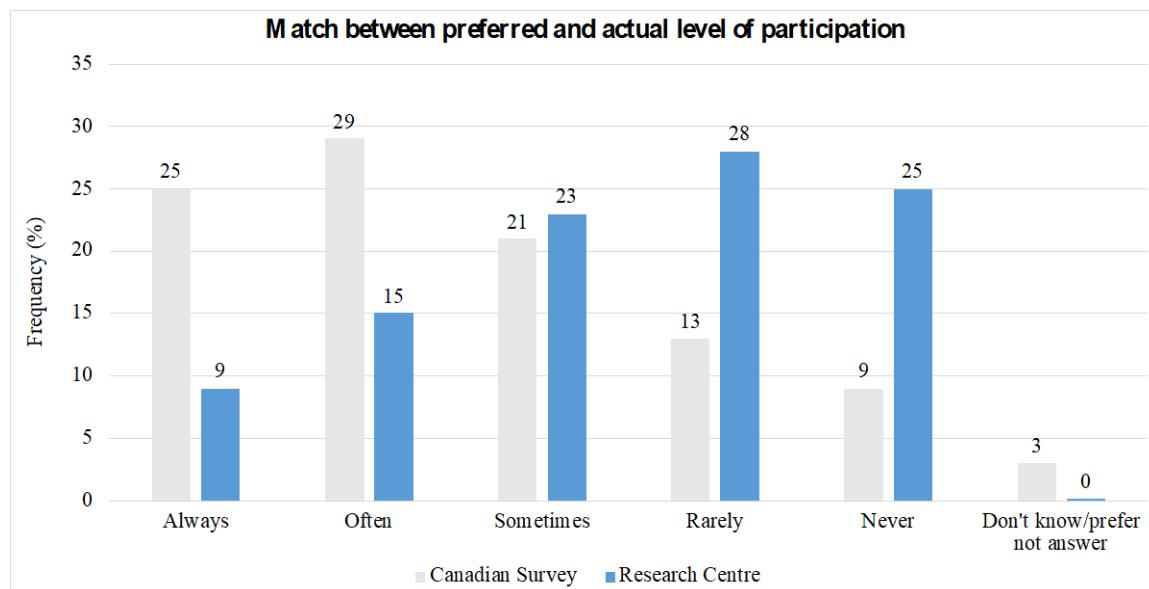


Figure 1. Comparison of the answer frequencies (in percentage) between the Canadian survey and our survey for each question; 1) Choices discussed; 2) Advantages/disadvantages presented; 3) Asked about ideas/preferences; 4) Asked about ideas/preferences; 5) Asked about preferred option.

Results and Discussion

What emerged most were the advantages of exchange in a virtual event, such as the fact that it was easy for people to attend from the most isolated or distant locations. Participants also noted repeatedly that they appreciated the fact that citizens were the heart of the event and organization. Participants' feedback is available in the published activity report available in French (CIUSSS-CN & VITAM, 2021).

The engagement of patient-partners and citizens was also an added value for the organizers of this online scientific event. We observed it was important to engage highly available persons for the committee work to progress effectively into the planned schedule. In addition, although it is well-known that engaging patients in research involves more time and more money than not engaging them (Domecq et al., 2014), their engagement should remain meaningful for a good partnership to develop and to take full advantage of their valuable contributions. However, we must keep in mind that we are all citizens and we have all the potential to become a patient and even a patient-partner in our lives.

Participants in our live survey (engagement strategy) experienced even less SDM than participants in the 2017 pan-Canadian survey (Figure 1) (Haesebaert et al., 2019). Two possible reasons for this are that a) our conference was held in the Province of Quebec which was shown in this previous study to be a factor associated with less SDM; and b) our conference was held almost a year into the Covid-19 pandemic during which, as a 2020 study showed, SDM was more difficult due to reduced face-to-face contact, fear of infection and overworked health professionals (Abrams et al., 2020). A limitation of our study was that we ran short of time for reporting back for breakout sessions. In a future conference we will plan for citizens from breakout discussion rooms to report back and then become impromptu speakers on a panel to discuss their reflections.

Since this conference, our research center has developed initiatives to increase interprofessional-SDM which are part of the global movement of citizen engagement. Working together to scale up SDM and to construct strong bridges between citizens and the health and social service community will lead to successful engagement such as at our

online event. To sum up, we hope that the interprofessional community takes action to enhance dissemination of the SDM approach through initiatives such as virtual conferences that include also patients' and citizens' voices, with their knowledge and experience forefront, during the pandemic and beyond.

Conflict of interest

None

Ethics approval

Research ethic committee of the Centre Intégré Universitaire de Santé et de Services Sociaux de la Capitale-Nationale (CIUSSS-CN) #2022-2396 has approved the project.

Consent to participate

None

Consent for publication

All authors have consented to publish.

Availability of data and materials

Not applicable

Author contributions

Study design: VB; KP and FL

Data collection: -

Data analysis: VB

Manuscript writing: VB wrote the first draft of the manuscript and the submission. All authors listed read, provided feedback on and approved the final manuscript.

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