


# People With Lived Experience at the Centre of Canadian Stroke Best Practice Recommendations: A Model for Guideline Developers

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## Abstract

Actively engaging people with lived experience (PWLE) in stroke-related clinical practice guideline development has not been effectively implemented. This pilot project evaluated the feasibility, perceived value, and effectiveness of the Community Consultation and Review Panel (CCRP), a new model to engage PWLE in the writing and review of Canadian Stroke Best Practice Recommendations. Responses to a standardized evaluation tool indicated that participants perceived the CCRP as valued, impactful, effective, and beneficial to stroke care. This project successfully demonstrated that values, experiences, and recommendations of PWLE can be effectively incorporated into guideline content and is applicable to all guideline development processes.

## Keywords

stroke, patient engagement, clinical practice guidelines, person-centered care, people with lived experience, rehabilitation, transitions of care, perceptions of care

## Introduction

Over the past decade, there has been a concerted international effort to prioritize patient, family member, and informal caregiver engagement at all stages of health-care planning and delivery (1,2). A person-centered approach extends beyond the person experiencing the medical event or condition to include the perspectives and contributions of individuals, caregivers, families, and communities (3). A fundamental aim of person-centered care is the active participation of people with lived experience (PWLE) in the development of clinical practice guidelines (4,5) and the research they are based on. This objective recognizes the value of the unique insights, experiential knowledge, and needs of PWLE with respect to their health condition and its treatment, personal goals and priorities, as well as their ground-level experience navigating the health-care system.

The most recent quality standards for guideline development strongly advocate for public and patient engagement in

writing and review (6,7) as there is evidence to suggest that engagement is feasible and generally perceived as a positive experience for the participants involved (8,9). However,

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determining the best method for this engagement continues to be an avid avenue of study (4,10,11) as criticism has been directed at some approaches deemed too tokenistic (12,13) and lack reliable evaluations.

We developed an inclusive and integrated model of engagement of PWLE for guideline development, named the Community Consultation and Review Panel (CCRP). The aim of this pilot project was to evaluate the feasibility, acceptability, perceived value, and effectiveness of this new engagement model in the update of the 2 components of the Canadian Stroke Best Practice Recommendations (CSBPR) Rehabilitation, Recovery and Community Participation module (14,15).

## Method

This pilot study of the feasibility, acceptability, perceived value, and effectiveness of the CCRP model was a nonrandomized mixed methods design, with purposeful recruitment of members. This study adhered to the Standards for Reporting Implementation Studies (Supplementary File 1). The CCRP model was conceived in consultation with several PWLE and was built as a reciprocal and collaborative knowledge sharing process between the CSBPR scientific writing group and a CCRP of PWLE. A review of the literature was conducted to identify and assess other models of engagement in guideline development. People with lived experience helped refine the model throughout the methodology development, implementation of the process, and evaluation. Table 1 describes the critical path and key implementation elements of each phase of the CCRP model with a detailed methodology for replication provided in Supplementary File 2.

## Results

### Participants

The first CCRP (*Rehabilitation and Recovery following Stroke*) was composed of 5 females (mean age: 41.8 years) and 4 males (mean age: 57.3 years), including among them 7 patients and 2 caregivers from 7 Canadian provinces. A total of 6 teleconferences were held with the group. The second CCRP (*Transitions and Community Participation following Stroke*) was composed of 5 females (mean age: 41.8 years) and 3 males (mean age: 52.5 years), representing 6 patients and 2 caregivers from 7 provinces. A total of 3 teleconferences were held with this group as there was less content.

The Heart and Stroke Foundation of Canada staff reported spending an average of 3 to 4 hours per week throughout the pilot study for participant recruitment and management, agenda and content preparation, and meeting facilitation. Staff also spent time on notetaking, feedback gathering, and synthesis of materials. The scientific writing group liaison reported spending on average 1 hour per week in preparation and participation on CCRP phone calls. They reported high satisfaction and active engagement with the process.

### Evaluation of CCRP Model

At the midway point of the first CCRP, 7 of 9 participants (78%) completed the online survey. They all *strongly agreed* or *agreed* on most elements of the evaluation tool. One person rated *disagree* on having enough information to contribute to the discussion, attributed to the relevance to their experience (eg, they did not receive certain rehabilitation therapies and therefore could not comment on them).

Six of the 7 individual participants who were on both panels responded to the final evaluation of the CCRP model (75% response rate); one individual member and the husband–wife pair were unable to complete the evaluation (n = 3). Figure 1 summarizes the responses of CCRP members to the 14 Likert scale questions from the final evaluation of the CCRP model. All participants who completed the evaluation, *agreed* or *strongly agreed* that they were satisfied, felt their participation would make a difference and that the panel achieved its objective. The majority of respondents (n = 5, 83%) *strongly agreed* that their views were heard, and all of the respondents *strongly agreed* (n = 3, 50%) or *agreed* (n = 3, 50%) that they were able to express their views freely.







Subjective feedback was positive, with CCRP members highlighting the value of meeting other PWLE, being able to share their stories in a safe environment and having their experiences benefit others with stroke. Expressed concerns were related to technical quality of the conference calls and the webinar program on their own computer systems, and one member where English was their second language. Inputs from the CCRP were integrated throughout the relevant CSBPR modules, particularly in the Rationale, System Implications, and Performance Measures sections. Supplementary File 3 provides all responses by CCRP members to the open-ended questions from the final evaluation time point (n = 6).

The scientific writing group liaisons and program staff reported that CCRP input was included in as many stages of the process of guideline revision as possible. They rated *strongly agree* to questions regarding their interest in further training on public and patient engagement; and agreed that as a result of the experience they would be more comfortable in leading public and patient engagement activities in the future, and that the process was a good use of program resources and enhanced decision-making.

## Discussion

Engaging PWLE in clinical practice guideline development in a systematic, meaningful, and measurable way has not been previously reported. This pilot project successfully implemented a new engagement model and demonstrated that the values, experiences, and recommendations of PWLE can be effectively incorporated into guideline content and is applicable to all guideline development beyond the scope of stroke.

**Table 1.** Critical Path for a Community Consultation and Review Panel (CCRP).<sup>a</sup>

Phase	Goal	Key Elements and Activities
 Phase 1	Member selection and onboarding	<ul style="list-style-type: none"> <li>• Call for volunteers within online Facebook Community of Survivors and Care Supporters Community</li> <li>• Direct invitations to engaged volunteers</li> <li>• Telephone interview and psychometric self-assessment screening</li> </ul>
 Phase 2	Orientation	<ul style="list-style-type: none"> <li>• Selection and offer letters</li> <li>• Completion of confidentiality and conflict of interest declarations</li> <li>• Member introduction and sharing of stroke experiences</li> <li>• Introduction to stroke best practice guideline development structure and processes</li> <li>• Creation of experiential journey map that aligns to scope of guideline (eg, rehabilitation)</li> </ul>
 Phase 3	Guideline content review and feedback meetings	<ul style="list-style-type: none"> <li>• Review of module topics and recommendations, share experiences, receive inputs, and suggestions</li> <li>• Participants record thoughts and feedback before and after discussion on feedback form and submit to facilitator at end of review stage</li> <li>• Sharing of feedback and information between scientific writing group and CCRP at every meeting of each group by liaison members</li> <li>• Mid-point evaluation</li> </ul>
 Phase 4	Integration of information into final documents, review by group	<ul style="list-style-type: none"> <li>• All feedback from CCRP reviewed and integrated into each module section as appropriate</li> <li>• Final draft module provided to CCRP members for review and additional comment</li> <li>• Members named as part of acknowledgment section of publication and in participant list in module</li> </ul>
 Phase 5	Knowledge translation and resource development	<ul style="list-style-type: none"> <li>• Development of public infographic that include highlights and key messages from guideline module</li> <li>• Participation in webinars and learning events for health-care providers and people with lived experience</li> <li>• Discussions within online communities about content and actions for self-management based on module</li> </ul>
 Phase 6	Evaluation	<ul style="list-style-type: none"> <li>• At mid-point of Phase 3 and at completion of module: <ul style="list-style-type: none"> <li>○ Standardized Patient and Public Engagement Evaluation Tool engagement evaluation tool completed online (anonymous)</li> <li>○ One on One interviews between each participant and facilitator for additional thoughts, inputs, and areas where participant may require additional support</li> </ul> </li> </ul>

Abbreviation: CCRP, Community Consultation and Review Panel.

<sup>a</sup>Detailed methodology for replication of the Heart and Stroke CCRP model in Supplementary File 2.

The goal of the CCRP model was to facilitate development of specific practice recommendations that are grounded in real-life experience and the unique needs of people with stroke while maintaining scientific rigour, and applicability to those directly impacted by the recommendations—people who have had a stroke, their families and caregivers, as well as the health-care professionals caring for them. The model provided members with opportunities to regularly review and offer feedback on draft recommendations from the scientific writing group, provide context related to their values and preferences in stroke care to help inform what person-centered care meant in the context of their lived experiences. This is a significant advancement

from previous models where engagement of PWLE as members of the writing groups was minimal and they were often disengaged, and stated that they felt they had little to contribute during the discussions about the available evidence, it was difficult to speak up during conference calls, and they sometimes felt dismissed by other writing group members when they did comment.

Participation in the CCRP process was perceived as a positive and impactful experience and enabled PWLE to also act as knowledge translation ambassadors through the codevelopment of lay language resources and education tools for PWLE and caregivers. Respondents felt that their feelings and experiences were acknowledged, and they enjoyed



**Figure 1.** Evaluation of the CCRP model. Responses to the Likert scale questionnaire administered to Community Consultation and Review Panel (CCRP) members during the final evaluation of the model.

the opportunity to connect and hear the experiences of other PWLE to develop stroke recovery strategies and recommendations. The writing group liaison stated it was very meaningful and a privilege to work closely with PWLE and understand the impact of the recommendations from their vantage point. Incorporating feedback from the CCRP helped to highlight areas within the guidelines that were considered to be of high importance and value by PWLE, family members, and caregivers. Health professionals who use these guidelines can utilize this feedback to provide a person-and-family centered approach.

This was a pilot study and the sample size was small. We have now engaged 2 additional CCRP groups in updates of the secondary prevention and acute stroke modules and engagement and feedback has been positive, reinforcing this is an effective model. The CCRP model has been approved for all new and updated modules as part of the Seventh Edition of the CSBPR. We will continue to refine implementation and evaluation of this model.

## Conclusions

The overall success of this pilot project established the feasibility and perceived benefit of employing a participatory and collaborative model, the CCRP, to actively engage PWLE in clinical practice guideline development, including all stages from writing to review and dissemination/knowledge translation. The results indicate that the CCRP increases PWLE engagement and provides guideline users

with valuable evidence-based recommendations supported by personal experiences, insights, and feedback. This model is pertinent and valuable for all guideline development across disciplines.

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## Authors' Note

Ethics approval was not required for this pilot study. All CCRP participants provided written consent to participate and completed a conflict of interest and confidentiality declaration prior to participation. All members of the CSBPR scientific writing group completed declarations of conflict of interest and confidentiality at the outset of the process.

## Declaration of Conflicting Interests

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## Supplemental Material

Supplemental material for this article is available online.

## References

- Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf.* 2016;25:626-32.
- Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect.* 2014;17:637-650.
- World Health Organization. WHO | Health Systems Strengthening Glossary [Internet]. WHO; 2019, [https://www.who.int/healthsystems/hss\\_glossary/en/index8.html#2](https://www.who.int/healthsystems/hss_glossary/en/index8.html#2)
- Armstrong MJ, Rueda JD, Gronseth GS, Mullins CD. Framework for enhancing clinical practice guidelines through continuous patient engagement. *Health Expect.* 2017;20:3-10.
- Loudon K, Santesso N, Callaghan M, Thornton J, Harbour J, Graham K, et al. Patient and public attitudes to and awareness of clinical practice guidelines: a systematic review with thematic and narrative syntheses. *BMC Health Serv Res.* 2014;14:321.
- Brouwers MC, Kho ME, Browman GP, Burgers JS, Cluzeau F, Feder G, et al. AGREE II: advancing guideline development, reporting and evaluation in health care. *CMAJ.* 2010;182:E839-842.
- G-I-N PUBLIC Toolkit: patient and public involvement in guidelines—guidelines international network [Internet]. 2012. <https://www.g-i-n.net/working-groups/gin-public/toolkit>
- Harding E, Brown D, Hayward M, Pettinari CJ. Service user perceptions of involvement in developing NICE mental health guidelines: a grounded theory study. *J Ment Health.* 2010;19:249-257.
- Serrano-Aguilar P, Trujillo-Martin M del M, Pérez de la Rosa A, Cuellar-Pompa L, Saavedra-Medina H, Linertova R, et al. Patient participation in a clinical guideline development for systemic lupus erythematosus. *Patient Educ Couns.* 2015;98:1156-1163.
- Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Recommendations for patient engagement in guideline development panels: a qualitative focus group study of guideline-naïve patients. *PLoS One.* 2017;12:e0174329.
- Díaz Del Campo P, Gracia J, Blasco JA, Andradás E. A strategy for patient involvement in clinical practice guidelines: methodological approaches. *BMJ Qual Saf.* 2011;20:779-84.
- van Wersch A, Eccles M. Involvement of consumers in the development of evidence based clinical guidelines: practical experiences from the North of England evidence based guideline development programme. *Qual Health Care.* 2001;10:10-16.
- Hahn DL, Hoffmann AE, Felzien M, LeMaster JW, Xu J, Fagnan LJ. Tokenism in patient engagement. *Fam Pract.* 2017;34:290-295.
- Teasell R, Salbach NM, Foley N, Mountain A, Cameron JI, Jong A de, et al. Canadian stroke best practice recommendations: rehabilitation, recovery, and community participation following stroke. Part one: rehabilitation and recovery following stroke, 6th edition. *Int J Stroke.* Epub ahead of print 27 January 2020. doi: 10.1177/1747493019897843.
- Mountain A, Patrice Lindsay M, Teasell R, Salbach NM, de Jong A, Foley N, et al. Canadian stroke best practice recommendations: rehabilitation, recovery, and community participation following stroke. Part two: transitions and community participation following stroke. *Int J Stroke.* Epub ahead of print 27 January 2020. doi: 10.1177/1747493019897847.

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