

Supplementary File 2

Supplementary Methods

Detailed methodology for replication of the Heart & Stroke CCRP model

Community Consultation and Review Panel Participant Recruitment and Orientation

The CCRP recruitment strategy was developed to ensure that participants collectively had lived experience relevant to the breadth of the module topic as a person with stroke or family member (e.g., attended inpatient rehabilitation; transitioned back to their home community, or cared for someone who met above criteria). Potential members participated in a screening interview and short self-assessment to determine their eligibility, fit, goals for participation, and ability to actively engage in discussions.

Community Consultation and Review Panel Implementation Process

Each CCRP ran in parallel to their respective scientific writing group who were responsible for the overall guideline update. A member of the scientific writing group and a HSFC staff member served as the liaison between the CCRP and scientific writing group, sharing information and input back and forth. The CCRP meetings were co-chaired by a HSFC staff member and a CCRP panel member and consisted of several one-hour video conference calls. The first meeting provided an opportunity for CCRP members to be oriented to the CSBPR and the review process. The scientific writing groups reviewed the updated evidence for each section and discussed revisions to recommendations. The updated information was then reviewed by the CCRP the following week where they added inputs and context based on their personal experiences and perspectives (patient, caregiver). The format of the meetings included an overview of the section by the scientific writing group liaison, then discussion with CCRP members, addressing questions of clarification, voicing their own experiences and proposed

content or edits for areas they felt should be addressed or included to enhance care, facilitate recovery, and strategies to support the individual and their family for each topic as appropriate (e.g. access to rehabilitation, use of evidence-based interventions, or patient and family education). All meetings began and ended with a “check in” in order to ensure participants’ thoughts and perceptions were captured and as an opportunity for further adjusting and refining the methodology.

Detailed notes were recorded by HSFC staff members, and the scientific writing group liaison reported the feedback to the scientific writing group at their next meeting. Throughout, CCRP input was continuously integrated directly into the Recommendations, Rationale, System Implications and Person-reported Outcome Measures sections as appropriate. Initially the scientific writing group met every two weeks and the CCRP every three weeks, so as not to overburden the CCRP members; however, in order to integrate feedback in a timely and seamless way, meeting frequency for the CCRP was increased to every two weeks, on opposite weeks to the scientific writing group. Meetings of the scientific writing group and the CCRP continued until all sections of the module were reviewed and consensus reached on the updated recommendations. Once the recommendation review phase was completed, CCRP members were engaged in ongoing activities to develop knowledge translation resources (e.g., infographics) and participate in dissemination.

There were three HSFC staff members who participated in the CCRP process – one served as a co-chair of the CCRP meetings, one who served as the liaison between the CCRP and the scientific writing group, and the third conducted the evaluations. Given the small number of HSFC staff, a formal evaluation was not conducted. However, HSFC staff met regularly to assess each stage of the CCRP process and to offer inputs on refining the model as it was delivered. HSFC staff members agreed that the model actively engaged people with lived experience in a meaningful way, added value to the guideline development process and final

content. Staff members directly involved with the CCRP reported gaining deeper insights into the experiences of people recovering from stroke and challenges they face.

Evaluation of Community Consultation and Review Panel Model

Structured and informal evaluations took place at the midway point and at the completion of the first CCRP (*Rehabilitation and Recovery following Stroke*). Since most members of the first CCRP carried over to the second CCRP (*Rehabilitation and Recovery following Stroke*), a final evaluation only was conducted for the second CCRP. The data collected from the two panels were aggregated. We adapted the Patient and Public Engagement Evaluation Tool (PPEET), a validated public and patient evaluation tool (1) to evaluate our CCRP model. Briefly, the PPEET utilizes a questionnaire-based format (including 14 closed-ended Likert scale questions and 4 open-ended questions) to assess four key principles of high-quality public and patient engagement: 1. integrity of design and process, 2. influence and impact, 3. participatory culture, and 4. collaboration and common purpose. Data collection and evaluation included key informant interviews, informal discussions and online surveys. Survey questions assessed participants' level of satisfaction, perceived impact and effectiveness of the CCRP process, and included an opportunity for participants to provide written comments and suggest improvements to the model.

At each evaluation timepoint, an anonymous online survey using the PPEET questionnaire was sent to all CCRP members to obtain feedback on the CCRP process. At the completion of Part One and Two of the CSBPR module a final survey was also sent to each scientific writing group liaison to obtain feedback on the impact of the CCRP on the CSBPR writing and review process, and their personal experiences as a liaison. HSFC staff also provided feedback throughout the process. Subjective feedback from all participants was collected and documented throughout the pilot study.

References

1. Abelson J, Li K, Wilson G, Shields K, Schneider C, Boesveld S. Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expect*. 2016 Aug;19(4):817–27.

INTERVIEW GUIDE

Questions for Prospective Advisors

Candidate Name:	
Interviewer Name:	
Date & Time of Interview:	

Instructions:

- Take time to review your assigned question(s);
- Take detailed notes when other team members are asking questions;
- Focus less on note taking when you are asking the question, as this will enable you to focus more on obtaining as much detail and information as possible;

Introduction:

- Explain that this is a screening interview to insure best fit for this particular panel and if selected, an offer letter will follow. If not selected, their name will be added to a list for future opportunities for engagement.
- Provide brief description of the organization and the history for external candidates;
- Provide an overview and aim of the CSBPGs;
- Mission and goals of the panel;
- Benefits of the participation including:
 - A chance to improve the quality & safety of health care services for you and your family;
 - The opportunity to be part of meaningful change and make a contribution;
 - Give a fresh perspective on problems and be part of creating innovative solutions.

Question:

Why are you interested in becoming a member on this panel? What are your personal goals for this experience?

Context:

Results/Outcome:

Evaluation:

Question:

In relation to your post-stroke rehabilitation experience; can you name three things that went well and three things that should have gone better?

Probing questions re: continuum points and stroke deficits experienced.

Context:

Results/Outcome:

Evaluation:

Question:

Are you willing to share your experiences related to stroke rehab with others (i.e. fellow PLWE and stroke experts and healthcare administrators, etc.).

How do you think your experiences would benefit the group (or the project)?

Can you provide an example?

Probing Questions (reference: <http://www.stmichaelshospital.com/pdf/patients/pe-learn-more-about-PFA.pdf>):

- See beyond personal experiences to contribute constructively
- Think broadly about more than one issue
- Share insights and personal experiences in ways others can learn from them
- Reflect on issues and priorities that are different than your own
- Speak comfortably in a group
- Provide constructive feedback
- Ability to participate in format required (webinar, survey, etc)
- Keep information confidential, as appropriate

Context:

Results/Outcome:

Evaluation:

Question:

Is there any other information that you think might be important for us to know about you? Any special skills that may be of assistance in this process?

Context:

Results/Outcome:

Evaluation:

Question:

Do you have any questions or concerns about what we expect of you?

- Review time commitments
- Other concerns raised by candidate
- Any current commitments might interfere?
- Methods to attend meetings – ie. Online technology

Context:

Results/Outcome:

Evaluation:

Question:

What is your preferred method of contact – email, phone or regular mail? Preferred meeting time / day of week?

Question:

Do you have any other questions for us at this time?

INTERVIEW SUMMARY

Questions for Prospective Advisors	Target Level	Candidate's level
	Strong	Strong
	Strong	Strong
	Strong	Strong
	Strong	Strong
TOTAL:	Strong	Strong

Selection Recommendation:

Signature of interviewer: _____