# A model for community-led peer-facilitated advance care planning workshops for the public

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#### **Abstract**

**Background:** The core to successful advance care planning (ACP) facilitation is helping people determine their values, beliefs and wishes, and understand substitute decision-making. Recognizing the potential for community members to support public awareness and education we developed a model of ACP education, whereby peer facilitators associated with community organizations host workshops that educate and assist members of the public with ACP. **Objectives:** Describe the development and evaluation of the model for community-led peer-

**Objectives:** Describe the development and evaluation of the model for community-led peer-facilitated ACP workshops for the public.

Design: Descriptive mixed methods.

**Methods:** A training curriculum and program model were co-developed with two community organizations that had been successful in delivering ACP workshops independently in their communities. Herein we describe a mixed-methods evaluation of three cycles of implementation and improvement of the model.

**Results:** The model centers on three key concepts; the right content (based around three steps Think, Talk, Plan), the right facilitator, and the right approach. A suite of tools was designed to support the three groups involved in the delivery of the ACP workshops: the public participants, the peer facilitators, and the community-based organizations. The peer-facilitator training addresses the facilitator's learning needs of ACP content knowledge, facilitation skills, and understanding change behavior. Training evaluation data from 106 facilitators confirmed that the curriculum prepared them to facilitate the workshops. Qualitative data revealed that support from organizations with established reputations in their community is critical, with mentoring from more experienced facilitators beneficial. **Conclusion:** Our model demonstrates the potential of community-led, peer-facilitated ACP

**Conclusion:** Our model demonstrates the potential of community-led, peer-facilitated ACP initiatives to enhance the capacity of community to upstream ACP conversations. Reaching a broader audience and creating a supportive, inclusive environment for individuals to comfortably learn about ACP can drive the much-needed culture shift to normalize ACP. Meaningful community engagement, empowerment, and partnerships are essential for the successful development and widespread impact of these initiatives.

# Plain language summary

A model for community-led peer-facilitated advance care planning workshops for the public Why was this study done?

Advance care planning (ACP) allows people to reflect on and share their personal values, goals and preferences as they relate to their future healthcare. Despite the benefits of doing ACP, the number of people who have engaged in ACP remains low. Traditionally, most ways of supporting people to engage in ACP have involved healthcare providers. In British Columbia, two community-based organizations had developed successful peerfacilitated workshops to engage and educate the public. In these workshops, non-expert

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members of the community (peer-facilitators) conduct interactive workshops that help members of the public understand and begin ACP.

What did the researchers do? We partnered with these two organizations to develop a training curriculum and other materials required to spread this approach to other community organizations throughout the province. The model is based on three key concepts: the right content, the right facilitator, and the right approach. The materials include a suite of tools for three groups: the public participants, the peer-facilitators and the organizations.

What did the researchers find? The training and suite of tools we developed successfully prepared community members ("peers") associated with community organizations to facilitate ACP workshops for the public. Support from community organizations is essential, and mentoring from more experienced facilitators is beneficial.

What do the findings mean? As a provincial organization we were able to successfully partner with community organizations to develop a model and spread the workshops provincially and confirm they were acceptable and effective, improving public access to information about advance care planning.

**Keywords:** advance care planning, community-based participatory research, community health education, community networks, Hospices, hospice societies

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#### Introduction

Despite the many established benefits of preparing in advance for future healthcare decisions, uptake of advance care planning (ACP) remains low in Canada. ACP is a process that helps adults to reflect on and share their personal values, goals, and preferences as they relate to their future healthcare. ACP can help prepare people for communication and medical decision-making, whatever their health status, so that they can make informed healthcare choices and have their healthcare wishes known and respected. Ideally, ACP should begin before health crises happen, so that it can inform 'goals of care' conversations and healthcare decision-making throughout the person's journey with illness.

Traditionally, most ACP education interventions rely on clinician facilitators and target 'patients' who are already engaged with the health care system. However, clinicians often report barriers to discussing ACP with their patients, such as lack of sufficient time to do so.<sup>5,6</sup> Interestingly, successful ACP facilitation typically focuses on helping people determine their values, beliefs, and wishes as well as understanding the concept of substitute decision-making. This type of facilitation does not necessarily require clinical

knowledge or expertise. That has led to increasing recognition of the role of non-clinicians, such as community members, in ACP facilitation.<sup>7–10</sup> These community-led ACP initiatives hold great potential in increasing public awareness and engagement, leading to a much-needed culture shift that makes ACP engagement the norm for everyone.<sup>10</sup>

In the Canadian province, British Columbia (BC), two community-based organizations, Comox Valley Hospice Society (CVHS) and the Community Engagement Advisory Network (CEAN) within Vancouver Coastal Health Authority, have emerged as leaders in community-led ACP education. They have been successfully delivering ACP education workshops for the public for over a decade. These workshops are facilitated by trained community volunteers, referred to in this article as 'peer-facilitators', as they are not required to be healthcare professionals. Both organizations' ACP programs had grown out of community engagement activities and were strongly committed to 'education by the public for the public'. These two programs have become exemplary models for other community organizations across the province seeking to establish similar ACP education initiatives to

benefit the communities they serve. While CVHS managed to spread their workshops to neighboring communities, they faced limitations in their capacity to support further spread.

To enable the wider adoption of these successful ACP programs throughout the province, the BC Centre for Palliative Care (BCCPC) partnered with CVHS and CEAN to develop a curriculum and an implementation toolkit for a provincial model for community-led ACP education based on their successful peer-facilitated ACP workshops. BCCPC is a provincial nonprofit organization funded by the BC Ministry of Health to accelerate the spread of innovations and best practices in three areas: palliative care integration; ACP promotion; and compassionate communities' mobilization. The primary objective of the partnership between BCCPC, CVHS, and CEAN is to enable and empower other community-based organizations in the province to adopt this ACP educational model and actively participate in provincial efforts to promote public awareness of and engagement in ACP. By sharing their expertise and resources, these organizations aim to create a more informed and proactive approach to ACP, benefiting the entire population of BC with improved person-centered care experiences.

#### Methods

# Model development and spread

BCCPC played a pivotal role in bringing together CVHS and CEAN to form a working group with the objective of creating a model for ACP education that could be shared with other organizations. By leveraging the collective expertise and community experiences of the working group, this partnership aimed to make ACP education more accessible and widespread in communities across BC. The driving force behind this collaborative work was a shared passion for the significance of public engagement in ACP, leading to better-informed healthcare decisions. The working group consisted of representatives from CVHS and CEAN (2-3 per organization, total five members) who shared their experiences in facilitating ACP education workshops in their communities. Additionally, BCCPC staff members (4) brought their knowledge and expertise in ACP, public education, and community development to the table. The working group met seven times over 5 months in early 2016. Throughout these meetings, the working group engaged in

structured and open conversations, employing a program analysis approach. They thoroughly analyzed each organization's existing ACP education program, identifying its core elements and key features as well as the factors that could enable or limit its successful implementation. Throughout the process, the emphasis was on incorporating the insight and experiences of the community, rather than solely relying on expertdriven perspectives. Interestingly, the program analysis of the CVHS and CEAN programs revealed several similarities in the key features of the peer-facilitated ACP workshops conducted by each organization. These shared elements included the conversational nature of the workshop, the use of storytelling, and sharing examples of completed advance care plans.

The program analysis findings informed the design and development of a provincial model for community-led peer-facilitated ACP education. This model included a facilitator training curriculum and a comprehensive toolkit of resources catering for the needs of the trained facilitators, host organizations, and public participants involved in ACP workshops.

The developed ACP education model was piloted in collaboration with nine community-based organizations over 10 months (from June 2016 to March 2017). These pilot organizations were recruited and financially supported through the first funding cycle of the BCCPC's Seed Grants Program. In addition to the peer-facilitator training provided by the working group, each pilot organization received \$3000 from BCCPC to cover the marketing and logistical expenses for delivering 2–3 pilot ACP workshops in their respective communities. Furthermore, the pilot organizations had access to coaching and mentoring by BCCPC's subject matter experts to enhance their implementation.

During the pilot phase, the feasibility and effectiveness of the developed model were evaluated as a part of a larger mixed-methods study. 11,12 Quantitative and qualitative data were collected from the trained facilitators, host organizations, and public participants.

Based on the positive results from the pilot phase, the spread and ongoing evaluation of the community-led peer-facilitated ACP model were facilitated through two subsequent funding cycles of the BCCPC's Seed Grants Program (November

2016–October 2017 and August 2017–March 2018). During these two cycles, 19 community-based organizations adopted the model, and each received \$3000 in funding and ongoing coaching to support the successful delivery and evaluation of at least three ACP workshops over a 10-month period. Some of the 19 organizations also participated in the first cycle, bringing the total number of organizations involved in the three cycles to 23.

In between the seed grants cycles, the evaluation results from the previous cycle were reviewed, leading to improvements in the model's training curriculum, workshop design, and toolkit. The key concepts and overall components did not change, but these iterative enhancements aimed to ensure the model's relevance and applicability to diverse community settings.

#### Model evaluation

Evaluation of peer-facilitator training: To assess the impact of the developed model on the peer facilitators who were trained as part of the three seed grants cycles, the facilitators were asked to complete pre- and post-training surveys (May 2016, October 2016, and October 2017). These surveys aimed to measure any changes in their knowledge, confidence, and skills related to ACP facilitation throughout the training process. See Appendix 1: Facilitator Training Evaluation Survey Questions.

Evaluation of public workshops: The impact of the model on public participants' knowledge and engagement in ACP and their overall experiences are reported elsewhere.<sup>12</sup>

Experiences of peer facilitators and host organizations: The trained facilitators as well as other staff members and volunteers from the community organizations shared their insights and perspectives through focus groups and individual interviews. These qualitative data helped capture the facilitators and hosts' experiences, challenges, and successes in implementing the ACP model within their respective communities.

#### **Ethics**

The program's development and pilot activities received ethics approval from the University of British Columbia Behavioural Research Ethics Board (#15-03335). Subsequent evaluation and improvements to the program were considered

quality improvement and therefore were not submitted for Research Ethics Board approval.

#### Results

The analysis of CVHS and CEAN's ACP education programs informed the development of the new community-led peer-facilitated model, including its key concepts and key components.

#### Key concepts of the new model

The working group identified three key concepts that are fundamental to the successful implementation of the ACP workshops:

1. The right content: The workshop content emphasizes the significance and benefits of ACP for every adult, especially the importance of having ACP conversations with the people we trust. The workshop's content is thoughtfully designed to convey consistent key messages, all guided by evidence-based facts about ACP (Figure 1). These key messages set the foundation for the information and conversations shared during the workshop.

The content is structured to cover key information about ACP using the key questions: What is ACP?, Why is ACP important?, Who should do ACP?, When to do ACP?, and How to do ACP? One notable feature of the workshop's content is its organization of the ACP process into three easy to remember steps: Think, Talk, and Plan. The 'Think' step refers to thinking about 'What matters most to you?' and 'Who could make healthcare decisions for you if you cannot?'. The 'Talk' step emphasizes the importance of ACP-related conversations: 'Discuss your thoughts with the people you trust, and your healthcare providers'. The 'Plan' step encompasses two activities: 'Record your wishes' and 'Share your plan with the people you trust and your healthcare providers'. The three steps follow the logical sequence of actions that people already know and follow when preparing for decision-making (Think, Talk, Plan). To further enhance the retention and recall of this information, the three steps and their underlying actions are presented in a simple three-bubble graphic with spaced repetitions of this graphic throughout the public workshop and related collateral including information materials and handouts (see Figure 2). The effectiveness and clarity of the Think, Talk, Plan formula and graphic and the

- ACP is a process of thinking, talking and planning (Think, Talk, Plan) that involves understanding and sharing your values, beliefs and wishes regarding health and personal care. It includes preparing for who would make these decisions for you if you cannot do so.
- ACP is an integral part of personal planning that every adult should do; it is part of being a healthy
  individual. The sooner you start the process, the better.
- As long as you are able to understand and communicate, you will make your own health-care decisions.
- ACP provides peace of mind to you and your family:
  - o it provides reassurance to your family that they know what you would want; and
  - o it provides reassurance to you that your health-care wishes are known.
- ACP is about communication with family, friends and health-care providers. Conversations about ACP get easier the more you have them.
- ACP is not just a one-time event; it is a process that you should revisit throughout your life. You can
  change your advance care plan at any time. You have options for how you want to express and record
  your wishes. Legal documentation may be helpful but not essential.

Figure 1. Key messaging.

supplementary collaterals were tested by members of the public during the pilot phase.

- 2. The right facilitator: The model outlines specific criteria to be used by community organizations to screen individuals from their staff or volunteers to be trained as peer facilitators. Two key criteria include experience with group facilitation and a passion for educating others about ACP. Additional criteria require that the facilitators agree to complete the training; demonstrate a solid understanding of ACP components and associated documents after the training; and commit to following the key messaging and workshop content provided during the training. While the peer facilitators can have any professional background, certain backgrounds such as teaching, healthcare,
- or roles with high requirements for customer service or public speaking are considered assets.
- 3. The right approach: Taking a person-centered approach is considered essential, with principles of connectedness and valuing the person forming its foundation. This approach enables the facilitators to build relationships with participants based on trust and respect. Specific strategies involved in this approach include sharing stories, using plain language in a conversational style, and respecting the participants' personal experiences and sensitivities. Peer facilitators also need to be aware of their boundaries, knowing when to refer participants to the appropriate resources if the participant's questions or situations fall outside their scope of practice.

#### Welcome Introductions Engage! Assemble Acknowledge: Adapt: **Use Stories** a comfortable the conversation your conversation Aids: Videos, Letters, & safe space is starting here today! to your audience Quotes, Pictures A process of: What is ACP? thinking about your values, beliefs, and wishes for future health and personal care, and It's a part of sharing them with the people you trust. life planning! It can include choosing who would make care decisions for you if you cannot. Why is ACP important? Who should do ACP? When to do ACP? Life's milestones Changes in health Final months/years For your For you For your Everybody! family health-care providers How to do ACP? Think Talk Discuss your What matters most to you? thoughts with: Who could make the people health and personal you trust; and care decisions your for you if you health-care Review cannot? providers. What's an advance care plan? Plan A record of what matters most to you Record your wishes. Contact list of potential Share your plan with: Temporary Substitute Decision · the people you trust; and Makers your health-care Optional legal forms: providers Representation Agreement Advance Directive Express appreciation Summarize BC Centre for Palliative Care Wrap Up @080 for conversation

Facilitating Advance Care Planning Information Sessions

**Figure 2.** Schematic of public ACP workshop content for facilitators. ACP, advance care planning.

While the model specifies the workshop content, a flexible mode of delivery of key ACP information was determined essential. The welcome and introductions at the beginning and a wrap-up at the end of the workshop remain consistent. However, the provision of key ACP information, categorized under the key question words *what*, *why*, *who*, *when*, and *how*, can be presented in any

#### Palliative Care Organizational Coaching Facilitator **Particinant Facilitator Training** Online & in-person workshop Řesources & Mentoring Resources Resources **Program Overview** Public handout Online learning **Program Overview** Facilitators have & pre-reading Organization Facilitator Guide summarizing access to the ACP guidance by In-person Guide Workshop information subject matter **Training** Planning checklist Schematic covered by the experts in ACP Workshop Marketing Sample templates **Presentation Slides** workshop and community development

Model Components

BC Centre for

Figure 3. Model components.

order that makes sense to the facilitator within the specific workshop. As conversations progress within the group, facilitators can provide further information as relevant topics arise organically, rather than rigidly adhering to a predetermined order. To facilitate this delivery approach, a schematic was developed for facilitators to refer to, containing the core information to be covered in a layout that aims to allow flexibility in presentation and order (Figure 2).

#### Model components

The model described below represents the culmination of comprehensive piloting and ongoing evaluation in collaboration with 23 communitybased organizations across the province of BC. Over a 3-year period, the model underwent two rounds of revisions, incorporating valuable feedback and insights from the diverse community-based organizations involved. Updates implemented due to the evaluation did not change the key concepts or overall model components. They included expansion of some pieces of the toolkit, such as the organization guide, and refinement of the in-person training workshop schedule.

The model comprises five key components: (1) online and in-person training for peer facilitators; (2) resources for peer facilitators; (3) resources for community organizations; (4) resources for public participants; and (5) access to coaching and mentoring (Figure 3).

Online and in-person training for peer facilitators. The training for peer facilitators addressed three core learning needs: ACP content knowledge, effective facilitation strategies, and behavior change approaches to promote and support participants' engagement in ACP activities.

To ensure an appropriate level of ACP content knowledge, trainees are required to complete an online learning module on ACP, utilizing an online course offered by a local health authority, Fraser Health. This module covers essential ACP concepts. Additionally, trainees are required to review and engage with the provincial ACP guide 'My Voice' to familiarize themselves with the information materials available to the public participating in their workshops. The in-person training day creates a supportive and inclusive learning environment for trainees, fostering a sense of community, and mutual learning among future facilitators. The training employs a personal, social, and knowledgeable delivery style, presenting models for conversations relevant to ACP. In addition to covering the key messages, steps, and resources of ACP, the training equips the trainees with valuable skills on how to manage challenging and derailing conversations that may arise during ACP workshops. Tips and insights from experienced facilitators further enhance their ability to

engage participants and foster productive discussions.

Through the training, the trainees also learn effective methods to encourage participants to move forward with their advance care plans and ACP-related conversations with the people they trust and healthcare providers. PowerPoint slides, stories, letters, and videos are used to structure and exemplify normalizing ACP conversations. Breakout groups guided by experienced facilitators provide opportunities for reflection, discussion, and sharing stories, passion, and wisdom about promoting quality of life through ACP. By integrating these various elements into the online and in-person training, peer facilitators gain a comprehensive understanding of not only the ACP content and curriculum but also the essential soft skills and facilitation techniques required to effectively guide individuals through the ACP process.

Resources for peer facilitators. Upon completion of the online and in-person training requirements, facilitators gain access to a comprehensive suite of resources designed to support the successful delivery and facilitation of the ACP workshops. One of the key resources available to facilitators is the ACP workshop schematic (Figure 2). The schematic serves as a one-page reference guide during the workshops, containing the core information to be covered. It offers a structured outline of the workshop, allowing facilitators to navigate the content seamlessly, and maintain a cohesive flow of information.

To complement the workshop schematic, facilitators are provided with a facilitator guide designed to assist them in preparing for the workshop. The guide expands on the topics included in the schematic, providing in-depth information on the core content of the workshop. It also includes facilitation tips, suggestions for interactive discussions with participants, and questions and topics for breakout group discussions. Additionally, the guide includes a glossary of key definitions, a resource list, and frequently asked questions to address any potential queries that may arise during the workshops. Facilitators also receive sample presentation slides that align with the workshop content. These optional presentation slides are intended to provide additional support and guidance, particularly for new facilitators who may feel apprehensive about adapting the content for delivery. While flexibility in delivery of the

content is encouraged, new facilitators appreciated the support provided by these optional presentation slides.

Resources for community-based organizations. To empower community-based organizations in successfully organizing, marketing, and hosting ACP workshop, two essential resources were developed: a program overview and a community partner guide.

The program overview contains background and context information useful to both the community organizations and their peer facilitators. This document outlines a high-level overview of ACP, including the consensus definition of ACP in the literature, the recent evolution of ACP concept, current emphases in ACP process, and how ACP is positioned in the pan-Canadian framework<sup>13</sup> as part of life planning alongside financial and retirement planning. It also provides a comprehensive overview of the model's development process, context, and objectives, along with outlining the roles and responsibilities of each partner involved in the delivery of the workshops (See Appendix 2: Roles and Responsibilities). Additionally, the program overview reiterates the model's three key concepts described earlier, highlighting their significance in the successful implementation of ACP.

The community partner guide serves as a practical tool to support organizations in effectively hosting the ACP workshops. The guide includes various checklists, providing step-by-step guidance for venue selection, and workshop planning. It emphasizes the importance of organizational support for peer facilitators and offers valuable advice on how to collaborate with other organizations, healthcare facilities, and businesses in their communities to enhance workshop outreach and impact. Moreover, the guide offers recommended processes and templates for registration and scheduling, marketing templates, and instructions for creating a communications plan to promote the workshops effectively. Lastly, the guide includes instructions and forms for conducting evaluations, enabling organizations to assess the effectiveness of their ACP workshops and identify areas for improvement.

Resources for public participants. A participant handout was developed, providing a concise and easy-to-read summary of the key concepts and information covered during the workshop. This

**Table 1.** Organization, peer-facilitator, and workshop metrics for cycles 1–3.

Cycle	Number of organizations	Number of peer facilitators trained	Number of workshops	Number of participants at workshops	Organization information**			
					Urban/ suburban	Rural	Remote	Hospice society
1. May 2016	9	47	37	566	4	4	1	9
2. October 2016	5	21	9	110	1	4	0	4
3. October 2017	12	34	26	369	3	5	4	9
Total	23*	104	69	1,045	7	11	5	19

<sup>\*</sup>Three organizations participated in both cycles 1 and 2, two organizations participated in cycles 1 and 3.

single-sheet handout serves as a reference for public participants to use after the workshop. It is designed to encourage and support participants to take proactive steps in their ACP journey.

Coaching and mentoring. To provide additional empowerment and support to peer facilitators and community-based organizations in their roles as facilitators and hosts, individual opportunities for coaching and mentoring were made available. These opportunities were conducted by subject matter experts in ACP education and community development with the aim of fostering a culture of continuous learning and improvement while creating a supportive environment. Through coaching and mentoring, facilitators and community organizations had the opportunity to further build on the knowledge and skills they acquired during the training and with the provided resources. The guidance offered by the mentors is not limited to ACP but extends to other aspects, such as partnership building, effective communication, and problem-solving. The goals of coaching and mentoring support are to strengthen the confidence and capabilities of facilitators and community organizations and help them navigate challenges, leverage opportunities, and adapt their ACP education approaches to the context of their communities.

#### Model evaluation results

Evaluation of peer-facilitator training. Across three seed grant funding cycles (June 2016–March 2018), a total of 104 facilitators affiliated with 23 organizations were trained, see Table 1 for details. Among these organizations, 19 (82.6%) were Hospice Societies, while the remaining 4 represented other types of community

organizations. Seven of these organizations were in an urban or suburban area (30.4%), 11 were in a rural area (>10,000 and <40,000 residents) (47.8%), and 5 were in remote areas (<10,000 residents) (21.7%).

The trainees were predominantly female (81%), and a significant proportion fell within the 61–70 age group (39.6%). About three-quarters of the trainees were volunteers at their respective organizations (73.6%). The majority had some previous experience in group facilitation (74%), and 14% had previous experience specifically in ACP facilitation. Refer to Table 2 for details.

Trainees' self-rated understanding of different aspects of ACP increased after the training. Prior to the training, approximately 55–65% of trainees agreed that they understood various aspects of ACP. After the training, the understanding of all aspects significantly increased, with 90–95% agreement across the board, except for the importance of ACP, which garnered 86.5% agreement. Additionally, trainees' confidence in facilitating ACP workshops also showed a substantial increase from 42.7% agreement before the training to 89.4% agreement after; see Table 3 for details.

Overall, the training was well received by trainees with agreement rates ranging from 87.1% to 94.5% for all statements, except for the statement regarding the adequacy of time, which received agreement from 72% of trainees. Notably, the rating for time adequacy was substantially lower for cycle 1 (55%) compared to cycles 2 and 3 (95% and 83% respectively). In the facilitator training for cycle 1, one of the morning's activities overran, and so the agenda for the rest of the

<sup>\*\*</sup>Urban/suburban defined as <40,000 residents, rural as >10,000, and <40,000 residents, remote as <10,000 residents.

**Table 2.** Demographics of peer facilitators trained.

n (%)	Cycle 1, <i>n</i> = 47	Cycle 2, <i>n</i> = 21	Cycle 3, <i>n</i> = 38	Total, <i>n</i> = 106	
Gender (female)	36 (76.6%)	18 (87.5%)	32 (84.2%)	86 (81%)	
Age					
19–30	0 (0%)	0 (0%)	3 (7.9%)	3 (2.8%)	
31–40	1 (2.1%)	0 (0%)	4 (10.5%)	5 (4.7%)	
41–50	11 (23.4%)	3 (14.3%)	2 (5.26%)	16 (15.1%)	
51–60	14 (29.8%)	4 (19%)	6 (15.8%)	24 (22.6%)	
61–70	18 (38.3%)	8 (38.1%)	16 (42.1%)	42 (39.6%)	
71–80	2 (4.3%)	6 (28.6%)	7 (18.4%)	15 (14.2%)	
81–90	1 (2.1%)	0 (0%)	0 (0%)	1 (0.9%)	
Role in organization*					
Volunteer		16 (76.2%)	23 (71.8%)	39 (73.6%)	
Staff		5 (23.8%)	9 (28.1%)	14 (26.4%)	
Facilitation experience**					
Yes, ACP		3 (14.3%)	4 (13.3%)	7 (14.0%)	
Yes, other topics		14 (66.7%)	16 (53.3%)	30 (60.0%)	
No		3 (14.3%)	10 (33.33%)	13 (26.0%)	

Role in organization and facilitation experience not asked for cycle 1.

session was compressed. The agenda was more closely adhered to in the subsequent cycles. Refer to Figure 4 for details.

Evaluation of public workshops. From June 2016 to March 2018, 137 ACP workshops were hosted by the 23 community-based organizations and facilitated by 106 trained peer facilitators. These workshops were attended by 2656 public participants. The results of the public participants' postworkshop and 4–6 weeks follow-up surveys are described elsewhere, 12 but confirmed workshops prompted engagement in ACP behaviors.

Experiences of peer facilitators and host organizations. Throughout the ongoing mentoring activities, and during the reporting and evaluation of the seed grant-funded ACP projects, peer facilitators as well as other staff and volunteers from the participating community organizations shared their experiences in implementing the ACP

model. The following themes emerged from their feedback, and illustrative quotes are provided.

The organization's standing within the community: Conducting ACP workshops for the public strengthened community awareness and acceptance of the participating organizations. This impact was particularly powerful for Hospice Societies, as the ACP workshops allowed them to reach a broader audience, breaking down barriers and enhancing people's understanding of their work and the scope of activities offered.

'The organization has been able to reach out to community members that may never have used Hospice services.'

'The workshops created an acceptance of the work we do in our community, which in turn, helps our residents to reach out more freely for necessary support.'

<sup>\*</sup>Cycle 3, n = 32.

<sup>\*\*</sup>Cycle 2, n = 20; cycle 3, n = 30.

**Table 3.** Evaluation data of trained facilitators' understanding and confidence before and after training.

Agree or strongly agree: n (%)	Cycle 1		Cycle 2		Cycle 3		Total	
	Before, n=46 (%)	After, n=45 (%)	Before, n = 20 (%)	After, n=20 (%)	Before, n=30 (%)	After, n=29 (%)	Before, n=96 (%)	After, n=94 (%)
I have a solid understanding of the basic concepts and terms within ACP	26 (56.5)	42 (93.3)	15 (75)	20 (100)	17 (56.7)	28 (96.6)	58 (60.4)	90 (95.7)
I understand why ACP is important	38 (82.6)	44 (97.8)	20 (100)	20 (100)	25 (83.3)	29 (100)	83 (86.5)	93 (98.9)
I understand the steps involved in ACP	27 (58.7)	44 (97.8)	14 (70)	20 (100)	15 (50)	28 (96.6)	56 (58.3)	92 (97.9)
l understand when a SDM is required	27 (58.7)	43 (95.6)	17 (85)	20 (100)	14 (46.7)	27 (93.1)	58 (60.4)	90 (95.7)
l understand how a SDM is identified	27 (58.7)	43 (95.6)	18 (90)	20 (100)	16 (53.3)	28 (96.6)	61 (63.5)	91 (96.8)
I understand what an advance directive is	21 (45.7)	38 (84.4)	17 (85)	20 (100)	16 (53.3)	27 (93.1)	54 (56.3)	85 (90.4)
I know where further information about ACP can be found*	30 (65.2)	44 (97.8)			12 (40)	28 (96.6)	42 (55.3)	72 (97.3)
I am confident in my ability to facilitate an ACP workshop with members of the public	20 (43.5)	39 (86.7)	10 (50)	19 (95)	11 (36.7)	26 (89.7)	41 (42.7)	84 (89.4)
*Question not asked in cycle 2. ACP, advance care planning; SDM, substitute decision-maker.								

The ACP workshops served as a catalyst for establishing strong and lasting relationships with other community partners, further amplifying awareness of the organization's activities and facilitating continued engagement with the community.

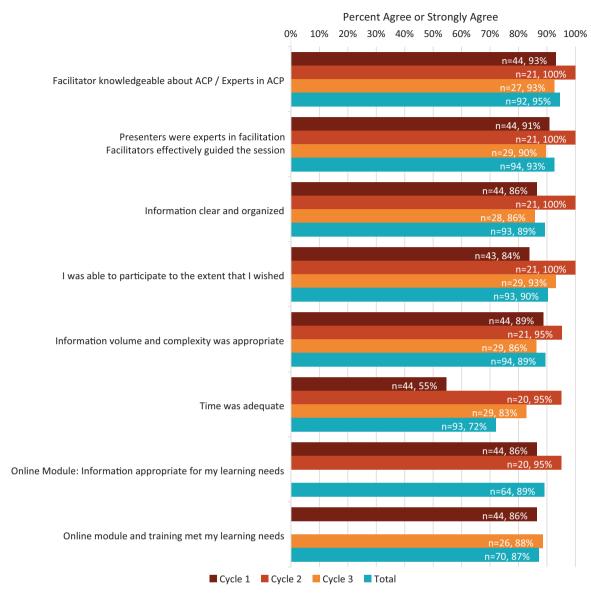
'Project partners know more about Hospice services and are able to speak about ACP as well as Hospice services to a greater number of their clientele'

Organizational support is integral: Adequate support for facilitators by their respective organizations was considered crucial for the success of the ACP workshops. When this support was not provided, projects struggled. This included planning and coordination support before and after the workshop such as scheduling, venue booking, registration, marketing, coordination, hosting, and evaluation. Furthermore, as the ACP workshops often served as a gateway for the public to learn about and access other services offered by the organization, in-person support by organizational representatives was also valuable to address enquiries about these additional services.

'It appears significant to have an anchor administrative person such as the Team Lead to supervise the volunteers, conduct follow-up meetings and reports re submitting evaluations, preparing marketing/ promotion notices, posters and announcements, and workshop materials.'

'Hospice staff presence is still recommended. This was also found to be necessary since referrals for further service from Hospice were sometimes done following the ACP workshops.'

Flexibility: As identified by the working group during the initial development phase of the model, organizations emphasized the importance of flexibility in delivering the workshop's key content to accommodate the capacity of their organization and meet the needs of their ACP program. This adaptable approach allowed for efficient



**Figure 4.** Percentage of trained peer facilitators that agreed or strongly agreed to evaluation statements in cycles 1–3 and overall.

utilization of various staff members or volunteers to effectively support the delivery of ACP workshops.

'People trickled in slowly. Our presentation adapted to fit into this kind of presentation. What worked is how we sat around in circle fashion and talked about ACP as far as wishes and values.'

'Make the format and information fit the community you are in'

'The learning has been strongest in terms of how to invite others to a hosted event. How to be a

welcoming facilitator and how to separate the roles of facilitator and host – learning they do not have to do everything.'

Facilitator experience: While some peer facilitators required time to become comfortable and confident in their role, most reported success in delivering the material, facilitating group discussions, addressing participants' questions, and directing participants to appropriate resources. Repeated practice and review significantly contributed to their growing comfort and confidence. One effective adaptation reported by newer facilitators was limiting the group size to a small group format for

initial workshops, and gradually increasing it as the facilitator gained skills and confidence. Additionally, mentoring from more experienced facilitators, whether within or outside of the organization, was highly valued and perceived as beneficial by newer facilitators. One organization reported that losing their more experienced facilitators part way through the project, was a major issue.

'Volunteers have basic facilitation skills and, even more important, confidence (and comfortable saying they don't know everything!)'

'Our confidence in delivering ACP sessions has greatly increased and feel that we can now be a resource for the community in the future.'

Shifted focus of ACP: Through the training, staff and volunteers reported a deeper understanding of ACP particularly the shifted focus of ACP to conversations rather than the legal aspects and completion of forms. This shift highlighted the community's suitability for supporting the public in initiating meaningful ACP conversations with the people they trust and healthcare providers. Facilitators reported that some public participants expressed interest in more information about legal aspects, but they managed to skillfully balance these requests by providing basic information or resources and emphasizing the core conversation content.

'I will always remember being encouraged not to go down 'the rabbit hole' of focusing the presentation on forms, but on the conversation. Once I learned that, everything else fell into place. . .'

'Our evaluations showed that the workshops most valued, were not the highly informative presentations on the legal ramifications of documents, but more the presentations around helping people practice using language to start 'the conversation'. These results highlighted that what is most important in ACP conversations is the language of care . . . 'language that expresses their care in meaningful end-of-life conversations'.

'Although the conversations are being stressed, participants often wanted more. For example, some people wanted to complete an ACP; others wanted more legal information. Resolved by making sure people knew of available resources.'

Sustainability: Organizations recognized the ongoing need and desire for ACP education and training activities within their communities, with the intent of continuing these activities beyond their seed grant-funded projects.

'Now that we have a core group of trained volunteers who have a well-defined structure/outline for these public workshops, the sustainability of the program should be relatively straightforward – we would just require event space and an ongoing budget for refreshments and photocopying/marketing.'

Ongoing and predictable activities were described as beneficial to capture and maintain the community's attention. Organizations reported that seasonal factors such as the weather and people's travel and activity patterns strongly influenced the scheduling of ACP workshops. Spring and Fall were identified as more favorable times to host these workshops.

'In terms of sustaining the program, it takes an ongoing, concentrated effort to capture and keep our audience's attention.'

'Our local library has agreed to host two ACP sessions a year which I will facilitate. We are aiming at May and October.'

For sustainability, two key factors were identified: facilitators turnover and funding. The turnover of volunteers and staff has a substantial impact on program sustainability, necessitating ongoing accessible opportunities to train and mentor new facilitators. Organizations also identified the needs for modest funding to cover the costs associated with advertising, refreshments, printing/photocopying handouts/resources, and venue hire.

'Maintaining a core group of facilitators will be a long-term problem. Like any volunteer group, members come and go. It is impractical and cost prohibitive to require new facilitators to be trained off site. Training existing facilitators to train new facilitators in their own community would keep the initiative viable in the long term.'

#### **Discussion**

The evaluation results demonstrate the positive impact of our model for community-led ACP education initiatives on the trained peer facilitators,

host organizations, and public participants involved in the ACP workshops. The model increased the *capacity* of peer facilitators by enabling them to gain the knowledge, skills, and confidence required to conduct engaging and successful ACP. Host organizations confirmed the *acceptability* of the model, reporting that hosting the ACP workshops was appropriate and beneficial.<sup>11</sup> Finally, the *efficacy* of the model was confirmed to prompt public participants to engage in ACP behaviors.<sup>12</sup>

A fundamental principle of our model is that ACP workshops are developed, delivered, and facilitated by members of the public for the public. This grassroots approach and the collaborative efforts among community organizations, including BCCPC, CVHS, CEAN, and the 23 early adopters of the model, were instrumental in both the development, evaluation, and subsequent widespread adoption of this successful model. Through these partnerships, we identified the key messaging, concepts and components of the model, as well as the needs of all those involved in the ACP workshops, including peer facilitators, public participants, and host organizations. Over a 3-year period, the model underwent two rounds of revisions, incorporating valuable feedback and insights from the diverse community-based organizations involved. This approach enabled us to create a model that truly resonated with the needs and preferences of the community, as it was developed based on actual requirements, rather than imposing a top-down, expert-directed approach. By prioritizing community needs and involving community members throughout, we ensured that the resulting model was both relevant and responsive. These partnerships were essential for establishing credibility, trust, and increasing the model's adoption.

The workshop's emphasis on facilitating ACP conversations rather than focusing on legal documentation aligns well with the peer-facilitator role, 11 as it does not require medical or legal expertise. Additionally, this approach is consistent with the literature recommendations which emphasizes the importance of focusing ACP on 'overall goals regarding medical care and on preparing the person to make informed choices based on what is most important to her or him' rather than completing legal documents.

It also recognizes the *significance of the ongoing* conversational aspect of ACP for every adult even as their health status changes. As a person's health

condition changes over time, the focus of ACP may gradually shift toward the development of a specific plan for future medical treatments.<sup>3</sup> For individuals with serious illness, consulting with healthcare providers and/or legal experts can be beneficial in creating an advance care plan that accounts for the trajectory of their illness and potential treatment options.

Our model addresses one of the priority actions within the Pan-Canadian ACP framework, <sup>13</sup> which encourages education of the public using consistent tools and simple messages that appeal to peoples' values and stimulate conversations about healthcare planning. It is also worth noting that this community-led, peer-facilitated model is a public health education initiative that aligns with the principles of compassionate communities. <sup>14,15</sup> In BC, such initiatives are considered key features of an ideal compassionate community, striving to create a supportive environment where ACP is embraced and valued as an essential aspect of life planning and living well.

Situating ACP education workshops within the community is *potentially advantageous for increasing equity in rates of ACP engagement*. This is particularly relevant for communities, such as indigenous or Black communities, that may have reasons to be skeptical of institutional involvement. Bringing ACP engagement initiatives away from the healthcare system creates an opportunity to establish meaningful connections and engage these communities more effectively, as the professional status and institutional links of clinicians may pose barriers to engaging these communities. Information delivered by peers can foster increased influence and trust.<sup>16</sup>

Our model is not the only one that utilizes peer (or lay<sup>17</sup>) facilitators in ACP education initiatives.7 Other models have used volunteer-based10 or paid<sup>18</sup> lay facilitators predominantly through individual support. One other model, implemented in Colorado, USA, uses peer facilitators in a group setting.<sup>7,19</sup> Fink et al. have reported success with this approach, engaging their communities and prompting ACP engagement among participants.<sup>7,19</sup> However, in this particular model, approximately half of workshops were co-facilitated by a nurse or physician, together with patient navigators (similar to our peer facilitators). As the main focus of their workshops was on choosing a substitute decision-maker and completing an advance directive7 it is possible

that this focus on legalities and documentation contributed to facilitators seeking additional support. In contrast, the focus of the ACP workshops within our model is fostering meaningful conversations, which may explain why our facilitators did not require 'expert' co-facilitation support in the same way. In alignment with this, other ACP interventions that have emphasized conversation, for example, by using cards or games, have been reported.<sup>8,20</sup>

While it is not surprising that most of the organizations that adopted our model were Hospice Societies (19/22),<sup>7,21</sup> it is important to note that *Hospice Societies are not the only type of community organization suitable for implementing this model.* For instance, church-based models have been described as effective in community-led ACP education initiatives.<sup>9,22–25</sup> A notable example of a successful community-based initiative partnered with churches to train African American 'lay health workers'.<sup>9,25</sup> Exploring a broader range of organizations to implement community-led ACP initiatives and investigating any differences in implementation experiences between organization types would be worthwhile future research.

A potential limitation of the implementation of our model so far is that both the peer facilitators and public participants of the workshops were predominately female, White, and educated.<sup>12</sup> Furthermore, the sessions were delivered only in English. To address this limitation, further work is needed to increase diversity among both peer facilitators and public participants of these workshops. Potential approaches include implementing culturally sensitive initiatives and targeting underrepresented communities in our recruitment and marketing efforts, and translation and adaptation of the toolkit. A successful example of this approach is demonstrated by Fink et al. 7 who effectively engaged a strongly Hispanic audience by specifically tailoring their outreach to these communities and hosting bilingual/in-language workshops.

There have been *other successful initiatives* that included trained volunteers or 'community health workers' integrated into the health system, <sup>16,26</sup> or healthcare team<sup>27</sup> who conducted 1:1 conversation with patients. These initiatives have shown great promise in increasing ACP engagement, but they require substantially more training and experience than our model, <sup>27</sup> making direct comparison challenging. Nonetheless, there are

notable similarities in the benefits of having nonclinicians facilitate ACP interventions, including the potential for increased community trust, enhanced rapport, and a more comfortable and open environment for participants.

#### Conclusion

Community-led ACP initiatives that involve trained peers in facilitation offer a powerful means to reach a broader audience and create a supportive and inclusive environment for individuals to comfortably learn about ACP and discuss their healthcare wishes. Our experience in BC has demonstrated the potential of these community-based initiatives to enhance the capacity of community to increase public awareness and engagement, driving the much-needed culture shift to make ACP engagement the norm for everyone. Through community engagement, empowerment, and partnerships, we have witnessed the successful development, adoption, and widespread impact of peer-facilitated ACP workshops.

Empowering public participants to initiate ACP conversations with their family members or healthcare providers is essential to fostering a culture of ACP. By taking a proactive approach through community-led initiatives, we can help individuals to have their healthcare wishes respected and followed, leading to person-centered care and support throughout their healthcare journey.

#### **Declarations**

#### Ethics approval and consent to participate

The program's development and pilot activities received ethics approval from the University of British Columbia Behavioural Research Ethics Board (#15-03335). Subsequent improvements to the program were considered quality improvement and therefore were not submitted for Research Ethics Board approval. Completion of questionnaires was considered as consent to participate.

Consent for publication Not applicable.

#### Author contributions

**Rachel Z Carter:** Conceptualization; Data curation; Formal analysis; Project administration; Writing – original draft.

**Eman Hassan**: Conceptualization; Supervision; Writing – review & editing.

**Pat Porterfield**: Conceptualization; Writing – review & editing.

**Doris Barwich**: Conceptualization; Funding acquisition; Writing – review & editing.

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# Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials Not applicable.

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### Supplemental material

Supplemental material for this article is available online.

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