Community organization perspectives on barriers and facilitators to Advance Care Planning in British Columbia

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Advance Care Planning and Community Organizations

- Advance Care Planning (ACP) is a process that supports adults to think about and share their values, goals and preferences as they relate to their future health care.[1]

- Community-based organizations are well placed for providing ACP services in their communities – and already are!

1. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. Journal of Pain and Symptom Management. 2017;53(5):821-832.e1. doi:10.1016/j.jpainsymman.2016.12.331

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Downloadable ACP resources for community organisations

Thousands of downloads every year

ACP facilitator training workshops

In 2019-2020, **221 community organisation volunteers and staff** were trained to deliver ACP workshops

Conversation game events

Over 2000 game booklets ordered to support over 100 game events in BC and across Canada

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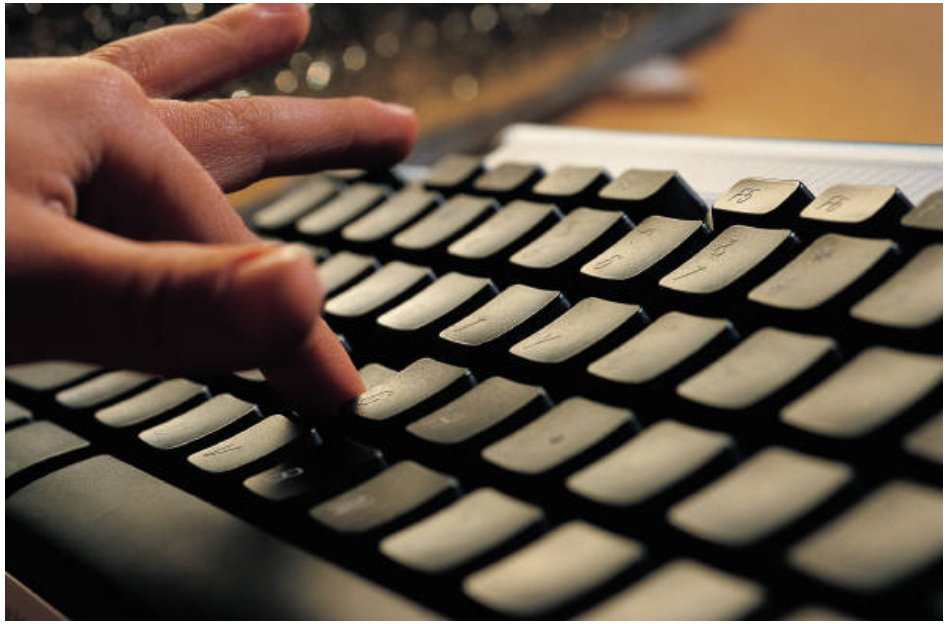
Research Questions

From a BC community-based organization perspective:

1) What are the most important barriers to ACP engagement?

2) What are the most important actions to take (facilitators) for ACP engagement?

Methods: Overview, Design and Analysis



June and July of 2020

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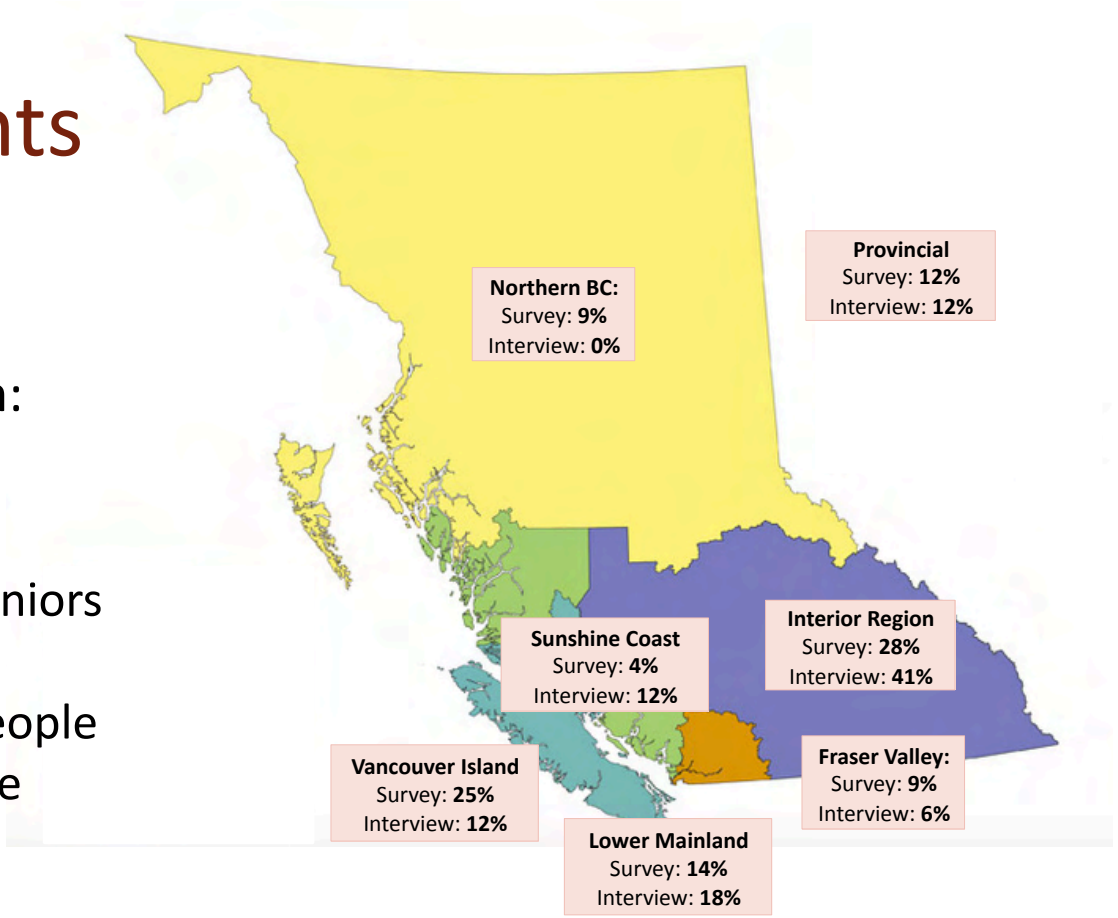
Results: Participants

- 57 survey responses
- 17 interviews
- Responses were mostly from:
  - Hospice Societies
    (Survey 44%, Interviews 53%)
  - Organizations supporting seniors
    (Survey 33%, Interviews 12%)
  - Organizations supporting people affected by a specific disease
    (Survey 9%, Interviews 18%)



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Important Barriers to Advance Care Planning

1. Lack of public awareness of ACP
2. Emotional difficulty of the conversation
3. Confusing terminology and complicated process
4. Belief that ACP is a one-time conversation to specify medical orders

- **ACP is a challenge to present in different cultural contexts***
- **Siloed approach to public ACP education***

**Emerged in qualitative analysis*

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ACP is a challenge to present in different cultural contexts

> "I don't actually know if there are cultural nuances that I should be aware of if I am speaking with someone from [the local First Nation] about their ACP."

> "A lot of places, it's a cultural decision….
>
> it's a family decision, how you move forwards in terms of treatment."

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Siloed approach to public ACP education

“[The Health Authority doesn’t] think that other agencies can provide [ACP education].”

“From a community perspective, we have more flexibility and can do things faster.”

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Important Facilitators to Advance Care Planning

1. Develop clear, simple messages
2. Improve ACP literacy
3. **Reframe ACP as part of life planning**
4. Simplify the documenting and transferring of ACP conversations
5. Integrate ACP conversations into the scope of practice for all health-care providers

- **Better collaboration between the health system and non-profits***

**Emerged in qualitative analysis*

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Reframe ACP as part of life planning

> *If [end-of-life & death] are part of our daily conversation, they become normal…*
>
> *They wouldn't be scary anymore, and we could talk over the things that we're worried about."*

> *You could work it into education practices, in terms of parent teacher associations."*

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Better collaboration between the health system and non-profits

> *"Local family health teams [could] collaborate with...local community organizations.*
>
> *Where [the] community organization is doing [an] ACP planning workshop once a week, and [the] physician is referring their patient to this workshop."*

> *"We're encouraging the physicians to refer people to us."*

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Significance of our study

Approach:

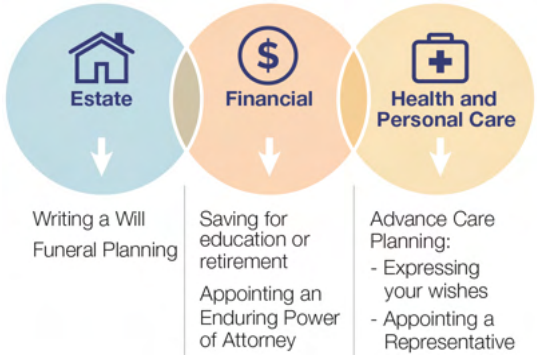
- The **community-based organization perspective** on ACP barriers and facilitators has not been specifically explored

Results:

- Community-based organizations feel that there is a **siloed approach to ACP education in BC**
- There is **frustration with current provincial ACP materials** is frequent, with a wish for clearer, simpler messages that are **adapted for different cultures and languages**
- Reframing ACP as part of life planning may be a **solution to the discomfort associated with end-of-life discussions, and non-profits are suited to support this**

What can I do to help?

Use culturally and linguistically appropriate ACP resources



Reframe ACP as part of life planning

Reach out to local community organisations to partner with them

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