



BC Centre for  
Palliative Care

Institute for Health System  
Transformation & Sustainability



# Environmental Scan

## Part 3 - Baseline End User Survey

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For the BC Centre for Palliative Care

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The views expressed herein do not necessarily represent the views of Health Canada.*

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## Survey Purpose

The purpose of the Survey Monkey Questionnaire was to collect available information on current ACP activities provided to the Chinese and South Asian communities, information about experiences with adapting other activities/interventions to the Chinese and South Asian communities. The survey invitation and link were widely distributed via email to BCCPC's community organizations. Those included on the BCCPC distribution list were encouraged to share the survey link with other contacts that we might have failed to include.

The information collected in the Survey Monkey Baseline Survey was used in conjunction the information collected during Part 1 of the Environmental Scan: Chinese and South Asian literature reviews help informed the questions used during Part 3 of the Environmental Scan: Key Informant Interviews.

## Distributed Survey Questionnaire

The survey introduction and questions are included below.

### Promoting Advance Care Planning among British Columbians with a Chinese or South Asian background - Baseline Survey

The BC Centre for Palliative Care invites representatives of organizations that have experience in delivering Advance Care Planning (ACP) education for the public to complete this short survey.

The survey will only take 10-15 minutes to complete.

Your inputs will be used to inform the development of a new initiative that aims to improve the uptake of ACP by the Chinese and South Asian communities in BC. The initiative is funded by Health Canada and led by the BC Centre for Palliative Care in collaboration with key partners. The initiative's focus is to translate and culturally-adapt an existing community-led education model where community volunteers and organizations are trained to deliver ACP information sessions. The initiative will also develop an online training module for healthcare providers addressing the cultural considerations for conducting ACP conversations with patients from a Chinese or South Asian background.

If you have any questions about the survey or the initiative, please contact Diana Cochrane ([dcochrane@bc-cpc.ca](mailto:dcochrane@bc-cpc.ca))



## Your Organization

**1. What is the name of your organization?**

**2. Among the people that you serve, do you often serve people with:**

**(Please select all that apply)**

- a Chinese background?
- a South Asian background?

**3. What area of BC does your organization serve?**

**(Please select all that apply)**

- Metro Vancouver
- Fraser Valley & Sunshine Coast
- Vancouver Island
- Interior region
- Northern BC
- Provincial

**4. What is your Name?**

**5. What is your role within your organization?**

**6. What is your Email Address?**

**7. May we contact you to: (Please select all that apply)**

- Ask for further information, including inviting you for a phone interview?
- Ask for help with the project in other ways? (for example: help with recruitment of Chinese/South Asian members of the public to provide feedback; trial the adapted model in your organization)
- Provide you with updates on the project's progress?

## Your Advance Care Planning Activities

**8. Is your organization currently conducting any activities related to Advance Care Planning?**

**(For example: information sessions; conversation facilitation; provision of brochures/leaflets)**

- Yes (please specify below)
- No
- If Yes, please specify

**9. What Advance Care Planning resources is your organization currently using?**

**(select all that apply)**

- Ministry of Health Resources
- Health Authority Resources
- BC Centre for Palliative Care Resources
- Resources from other organizations (please specify)
- Resources your organisation has developed (please specify)

**10. Have you experienced any language and/or cultural barriers in your delivery of programs and resources to people with a Chinese background?**

- Yes (please specify below)
- No
- Do not serve Chinese Community - please skip the rest of the questions on this page.
- If Yes, what were the barriers and how did you address them?

**11. In your opinion, what are some of the attitudes/reactions/feedback that people with a Chinese background have in relation to Advance Care Planning activities and resources?**

**12. Has your organization used Advance Care Planning materials/programs adapted/translated for people with a Chinese background?**

- No
- Yes, my organization adapted/translated the materials
- Yes, my organization used materials adapted/translated by others.  
Please specify the name of those who adapted/translated these materials:

## Your Education Experience with South Asian Community Members

**13. Have you experienced any language and/or cultural barriers in your delivery of programs and resources to people with a South Asian background?**

- Yes (please specify below)
- No
- Do not serve South Asian Community - please skip the rest of the questions on this page.
- If Yes, what were the barriers and how did you address them?

**14. In your opinion, what are some of the attitudes/reactions/feedback that people with a South Asian background have in relation to Advance Care Planning activities and resources?**

**15. Has your organization used Advance Care Planning materials/programs adapted/translated for people with a South Asian background?**

- No

- Yes, my organization adapted/translated the materials
- Yes, my organization used materials adapted/translated by others.

Please specify the name of those who adapted/translated these materials:

**16. Do you have anything else that you would like to share?**

## Completion/Thanks

We thank you for your time spent taking this survey.

Your response has been recorded.

## Organizations and Staff that participated in the Survey (n=25)

Hospice Societies	Staff Role
Canadian Hospice Palliative Care Association	Program Manager- ACP in Canada
Gabriola Home Hospice Program	Home Hospice-Volunteer Coordinator
Surrey Hospice Society	Lead/Support Education Coordinator
Nanaimo Community Hospice Society	Clinical Practice Educator-Palliative Care

Health Authorities	Staff Role
Fraser Health Authority	Social Worker (3)/ACP Team/Nurse/Clinical Nurse Specialist//Facilitator/Nurse Practitioner
Vancouver Coastal Health/Providence Health Care	Volunteer/Social Worker/Volunteer Coordinator
Interior Health Authority	Social Worker

Other Organizations	Staff Role
Kitsilano Neighbourhood House	Clinical Educator
New Directions	ESL Instructor
Multicultural Health Brokers Cooperative	Executive Director
BC Cancer	Director
Patient Pathways	Director
Alzheimer Society BC	Healthcare Navigator/Advocate
SA	Advisory Committee

- 80% of respondents serve people with a South Asian and Chinese Background.
- Organizations belonging to all regions of British Columbia are represented in this survey. (Metro Vancouver, Fraser Valley/Sunshine Coast, Vancouver Island, Interior, Northern, Provincial)

## ACP Activities (n=22)

Nearly 80% of participating organizations currently conduct ACP activities including:

### The Speak Up Campaign

Part of a larger initiative – ACP in Canada – and is overseen by a National ACP Task Group comprised of individuals representing a spectrum of disciplines, including health care, law, ethics, research and national non-profit organizations. This initiative includes

- Resource development for legal, long-term care, and community care settings
- Development of e-learning modules to support and train stakeholders in ACP facilitation
- Refreshed ACP National Framework
- Public Awareness and Education campaigning (social media)
- ACP Public Education/community presentations

### Community Outreach

- ACP Public Education
- BC ACP Toolkit for dying with dignity Canada
- Attending seniors fairs
- Information sessions on personal planning and transition into long-term care
- Support for caregivers
- ACP mentoring
- ACP engagement
- ACP Presentations
- Workshops on writing wills and organ donation

### Healthcare

- ACP/Serious Illness conversations with all patients/promote early goals of care
- LEAP core
- Training courses via health authority and Learning Hub/presentations
- Participation in health fairs
- Training courses on ACP community engagement

## Training Resources Used (n=21)

Organizations used resources from multiple organizations and agencies:

- Ministry of Health (71%)
- Health Authority (57%)
- BC Centre for Palliative Care (57%)
- Other
  - Speak Up
  - Brochures –
    - No CPR
    - ACP
    - What Matters Most to you (Translated into Chinese)
  - My Voice (most commonly used for Chinese)
  - Serious Illness Conversation
  - Hello Conversation Game
  - Nidus (Representation Agreement)
  - Empowered Patients & Empowered Caregivers: A guide to ACP
  - MOST Form- ACP/MOST video (11 min) Dr. Trevor Janz - click link to view [https://youtu.be/Y0TyhWQOf\\_8](https://youtu.be/Y0TyhWQOf_8)

## Chinese Community (n=20)

50% of participating organizations have experienced language and cultural barriers when delivering programs and resources to people with a Chinese background.

Barriers	Suggestions
<b>Unfamiliar with the topic of ACP</b>	
<ul style="list-style-type: none"> <li>• Unaware of ACP</li> <li>• Never thought of ACP</li> </ul>	
<b>Concept of ACP is unrelatable to the Community</b>	
<ul style="list-style-type: none"> <li>• The way ACP is explained does not resonate with the community</li> <li>• Out of social and cultural context</li> <li>• ACP is generic and applies to white, middle class, Anglocentric audience</li> </ul>	<ul style="list-style-type: none"> <li>• Language and cultural navigators can help clarify</li> <li>• One respondent said that Chinese members face similar challenges to other people</li> </ul>
<b>Avoidance of topic</b>	
<ul style="list-style-type: none"> <li>• Reluctant to discuss topic amongst the individual and the family members</li> <li>• Considered to be bad luck to talk about death and dying</li> <li>• People get upset when brought up</li> <li>• Deny that anything is wrong with them</li> </ul>	<ul style="list-style-type: none"> <li>• Using healthcare providers that speak the language/interpreters to explain ACP and why it is important</li> <li>• Validate the individual by acknowledging individual needs, values and beliefs</li> </ul>



Barriers	Suggestions
<ul style="list-style-type: none"> <li>• Don't understand why ACP needs to be discussed with family</li> <li>• Family asks clinicians not to tell elderly family members about their illness</li> </ul>	<ul style="list-style-type: none"> <li>• Easier to have the conversation with individuals and families after building a trusting relationship.</li> <li>• Clinicians sometimes resort to using non-specific terms to respect limited disclosure/indirect communication</li> <li>• Cultural sensitivity/humility and building lasting relationships</li> </ul>
<b>Wanting to talk about it but face challenges initiating</b>	
<ul style="list-style-type: none"> <li>• Want to talk about ACP, but difficult to initiate subject with loved ones, don't know how to approach concern</li> <li>• People want to know about resources, but never discussed ACP with family</li> <li>• Formal activities are resources are overwhelming and intimidating</li> </ul>	<ul style="list-style-type: none"> <li>• Group activities, people are more open and ask a lot of questions</li> <li>• ACP activities and resources need to be ongoing to cultivate a trusting relationship</li> </ul>
<b>Limited Resources</b>	
<ul style="list-style-type: none"> <li>• Proper conversations take a long time</li> </ul>	<ul style="list-style-type: none"> <li>• Need assistance to access resources and practical assistance in completing the plan</li> </ul>
<b>Language Barriers</b>	
<ul style="list-style-type: none"> <li>• Even though there are translators available some key concepts of ACP get lost in translation</li> <li>• There are multiple dialects and languages for Chinese people (Mandarin, Cantonese, English)</li> </ul>	<ul style="list-style-type: none"> <li>• Request specific dialect interpreters to address difference between Mandarin/Cantonese</li> <li>• Translated documents that are culturally sensitive and safe</li> <li>• Translating things could be waste of resources, if they could read their languages, chances are they can read English too</li> </ul>
<b>Shifting Responsibility/Deferring</b>	
<ul style="list-style-type: none"> <li>• Defer all decisions to family members when asked if they want to know what is happening with health</li> <li>• Dismisses attempts to discuss</li> </ul>	<ul style="list-style-type: none"> <li>• Generational and family dynamics need to be considered in ACP education ,activities, and resources</li> </ul>

## South Asian Community (n=19)

63% of participating organizations have experienced language and cultural barriers when delivering programs and resources to people with a Chinese background.

Barriers	Suggestions
<b>Unfamiliar with the topic of ACP</b>	
<ul style="list-style-type: none"> <li>Unaware of ACP</li> <li>Never thought of ACP</li> </ul>	<ul style="list-style-type: none"> <li>Ongoing dialogue, empowering community members, checking in with them about their understanding and finding out what would work best for them regarding interpretation seems most helpful.</li> <li>One respondent mentions that the issues are the same amongst all people</li> </ul>
<b>Concept of ACP is unrelatable to the Community</b>	
<ul style="list-style-type: none"> <li>The way ACP is explained does not resonate with the community</li> <li>Out of social and cultural context</li> <li>ACP is generic and applies to white, middle class, Anglocentric audience</li> </ul>	<ul style="list-style-type: none"> <li>Use Nurses and other staff that speak Punjabi and Hindi as cultural and language liaisons to help clarify concepts</li> <li>Train facilitator</li> </ul>
<b>Avoidance of topic</b>	
<ul style="list-style-type: none"> <li>Not ready to discuss</li> <li>Although many outreach attempts have been made by South Asian navigator (via radio, free workshops) there has been poor attendance and interest</li> <li>ACP is too related to death for this community</li> </ul>	<ul style="list-style-type: none"> <li>Using healthcare providers that speak the language/interpreters to explain ACP and why it is important</li> <li>Validate the individual by acknowledging individual needs, values and beliefs</li> <li>Easier to have the conversation with individuals and families after building a trusting relationship.</li> <li>Cultural sensitivity/humility and building lasting relationships</li> </ul>
<b>Wanting to talk about it but face challenges initiating</b>	
<ul style="list-style-type: none"> <li>Want to talk about ACP, but difficult to initiate subject with loved ones, don't know how to approach concern</li> </ul>	<ul style="list-style-type: none"> <li>Group activities, people are more open and ask a lot of questions</li> <li>ACP activities and resources need to be ongoing to cultivate a trusting relationship</li> </ul>



Barriers	Suggestions
<b>Limited Resources</b>	
<ul style="list-style-type: none"> <li>• Difficult to have a proper conversations take a long time</li> <li>• Translators take a long time, limited time</li> </ul>	
<b>Language Barriers</b>	
<ul style="list-style-type: none"> <li>• Difficulty simplifying ACP language, communicating importance of ACP</li> <li>• Using interpreters can be a barrier as it reduces relational aspect of care.</li> <li>• Family members that act as interpreters on behalf of the patient feel as though the healthcare providers do not trust them as family members, or shame their English language ability</li> </ul>	<ul style="list-style-type: none"> <li>• Having patient friendly documents to help patients and families understand ACP (no examples given)</li> <li>• Families usually come with someone who translates for them</li> <li>• Families members who speak English will often speak or interpret of behalf of the patient, feels that it is unnecessary to have an interpreter (especially if the interpreter is from the community)</li> <li>• Use translation service when needed</li> </ul>
<b>SDM and Shifting Responsibility/Deferring</b>	
<ul style="list-style-type: none"> <li>• Patient does not want to share opinions and asked to speak to children instead</li> <li>• Sometimes it can take a long time to identify a substitute decision maker when the patients can't speak for themselves</li> <li>• Fate is in the Hands of God whether they die or not, they don't necessarily need to outline their healthcare wishes.</li> <li>• Unsure if patient is making decision or if family is making decisions for them.</li> </ul>	<ul style="list-style-type: none"> <li>• Family meeting can be a more effective way for communicating, as the patient comes from a large family.</li> <li>• Acknowledge that even though there may be an identified SDM, decision making may still be shared amongst/influenced by the entire family</li> </ul>

## Chinese and South Asian Attitudes and Reactions to ACP and resources

There have been mixed reactions to ACP resources for both the Chinese and South Asian communities

### Positive

- Never experience any negative reactions or attitudes
- After the ACP education, the participants completed ACP conversations
- Thankful

### Neutral

- Not sure never asked
- None noticed
- Very individual, no common attitude or feedback

### Negative

- Apprehensive to discuss death and dying as its considered to bad luck
- Uncomfortable and not ready
- Upset when ACP is brought up
- Fear and denial