

Cultural & linguistic adaptation of Advance Care Planning public education for Chinese & South Asian communities

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Institute for Health System
Transformative & Sustainability



BC Centre for
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Presenter Disclosure

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No potential bias identified.



What is Advance Care Planning?

A process where you:

Think about and share your values,
beliefs and wishes for future care

to support informed health-care
decision making

to help you get the care that's right for you, even if you
are unable to speak for yourself

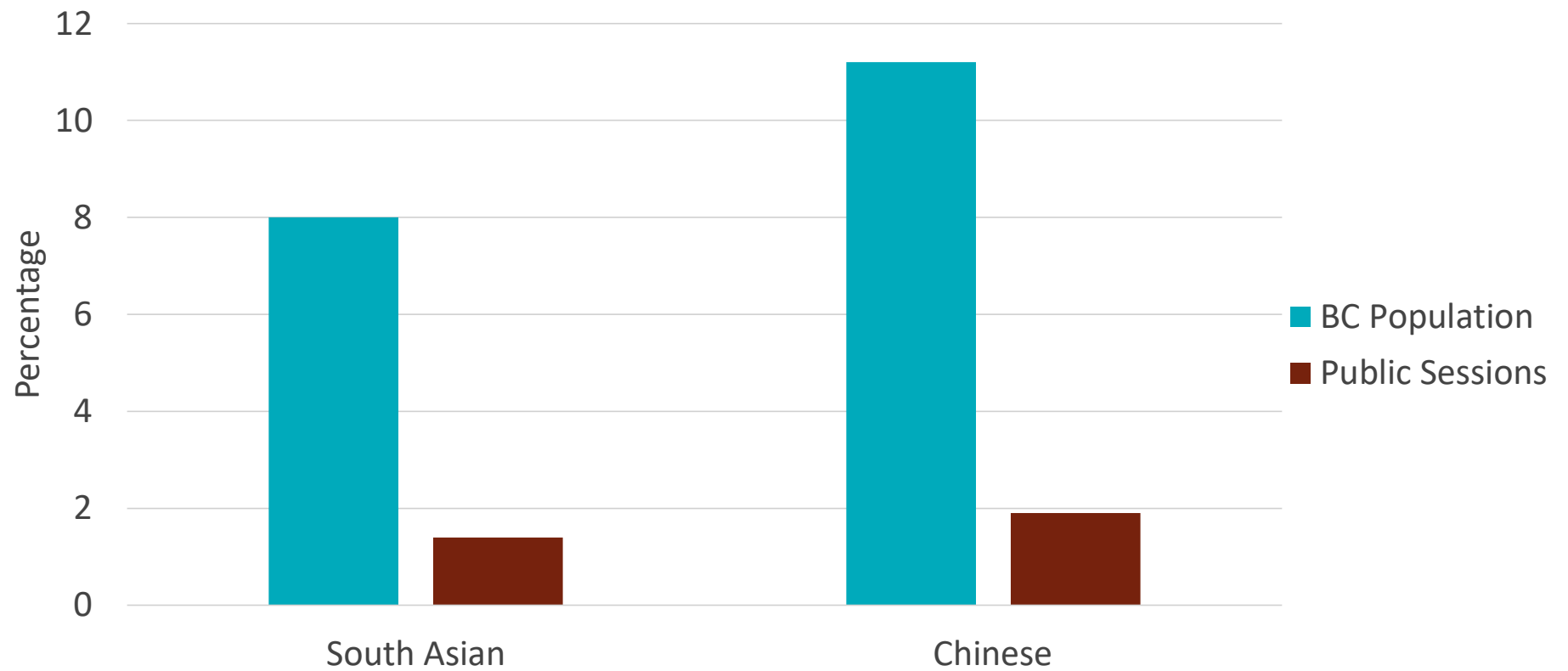
Adapted from Sudore et al, 2017, Journal of Pain and Symptom Management



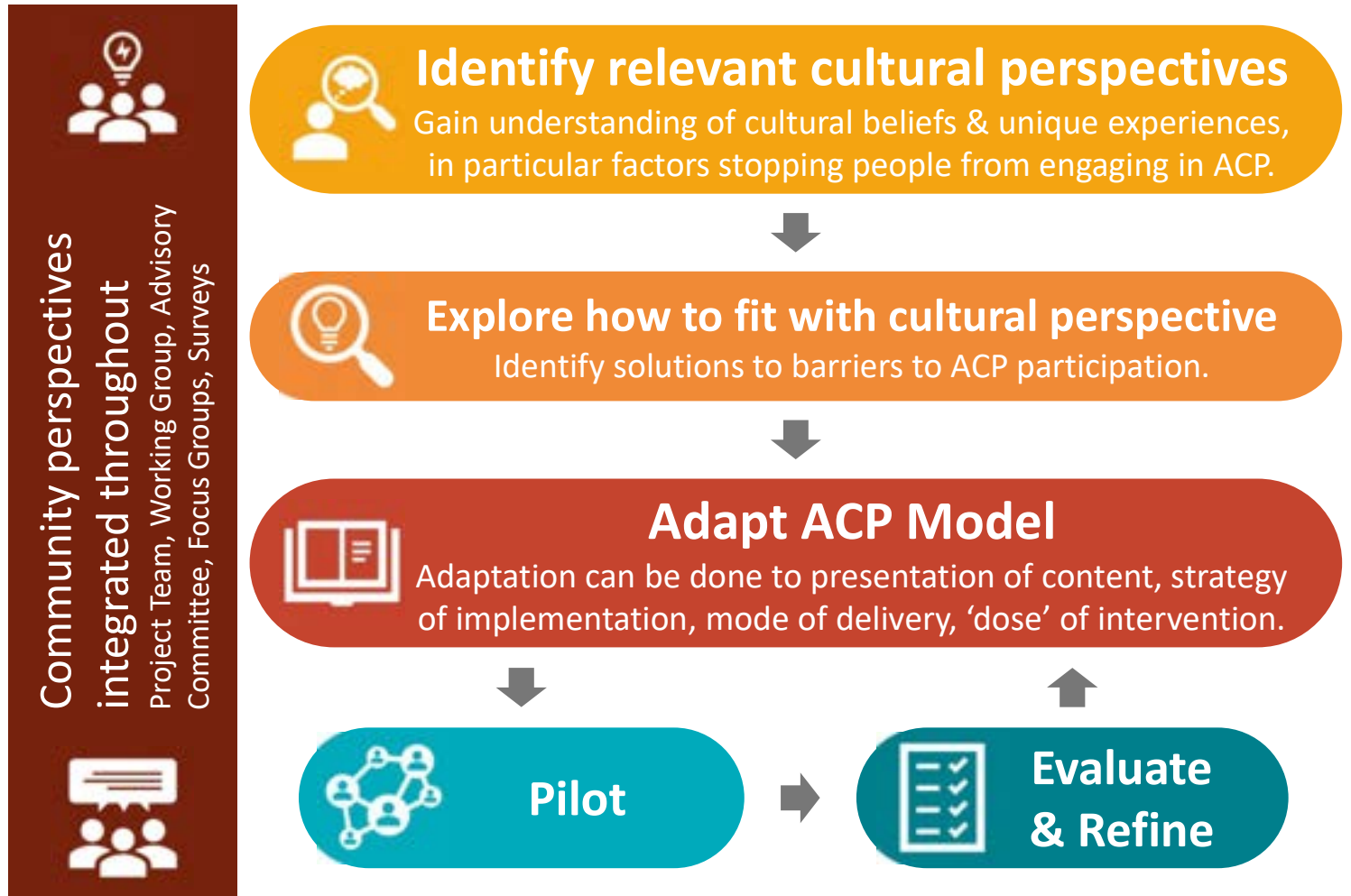
Community-led Advance Care Planning Model



The need for the project...



Adaptation Process



Cultural Perspectives



Key Findings: Common Barriers



ACP is an unfamiliar concept



Conversations about death and dying avoided/feared



Traditional gender roles



Language & literacy barriers



Preference for limited or no disclosure of diagnosis to patient



Lack of understanding of Canadian healthcare system



Key Findings: Chinese Community



Preference for indirect
and passive
communication style



Physicians are experts,
and best to make medical
decisions for patient



Frame ACP as
opportunity to learn,
and tool to avoid stress



Partnership with
reputable organisations



Key Findings: South Asian Community



Religion features prominently and religious leaders are top of the social hierarchy



Recognise and build on community capacity



Spread information through word of mouth



Acculturated people may still refer to original cultural beliefs when faced with critical life events



Key Findings: Common Suggestions



Use storytelling



Avoid assumptions about cultural beliefs. Recognise them as one aspect of preference.



Do not just frame around death



Use different motivations







Use organisations and facilitators to reach participants



Adaptation & Translation



Toolkit Adaptation - Themes

Problem	Solution
 <p>Concerns about reading level, health literacy level and cultural sensitivity in resources</p>	<ul style="list-style-type: none">• Toolkit-wide review of language• Focus on plain language
 <p>Specific information/considerations based on cultural values and practices</p>	<ul style="list-style-type: none">• Include stories and videos that are culturally applicable• Continued consultation with community members
 <p>Need for consistent and appropriate use of terms in other languages</p>	<ul style="list-style-type: none">• Step-wise translation, starting with key terms, through to sample scripts and public resources
 <p>Identification of information needs and preferred modes of information</p>	<ul style="list-style-type: none">• Translated web-based information• Translated documents to support legal form completion• Preference for single language handouts

Adapted Toolkit

Resources for: Organisations, Facilitators, Public Participants



Resources for organizations and facilitators



Resources for participants – Rep Agreements

What you need to know about enhanced representation agreements (section 9)




Part 1 of 3
A guide to legally appointing a substitute decision maker in B.C.

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What you need to know about being a representative in an enhanced representation agreement (section 9)



Part 2 of 3
A guide for people who have been asked to be legally appointed as a substitute decision maker in B.C.

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A guided tour of the BC government's representation agreement (section 9) form



Part 3 of 3
A guide for people who want to complete an enhanced representation agreement using the BC government's form.

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