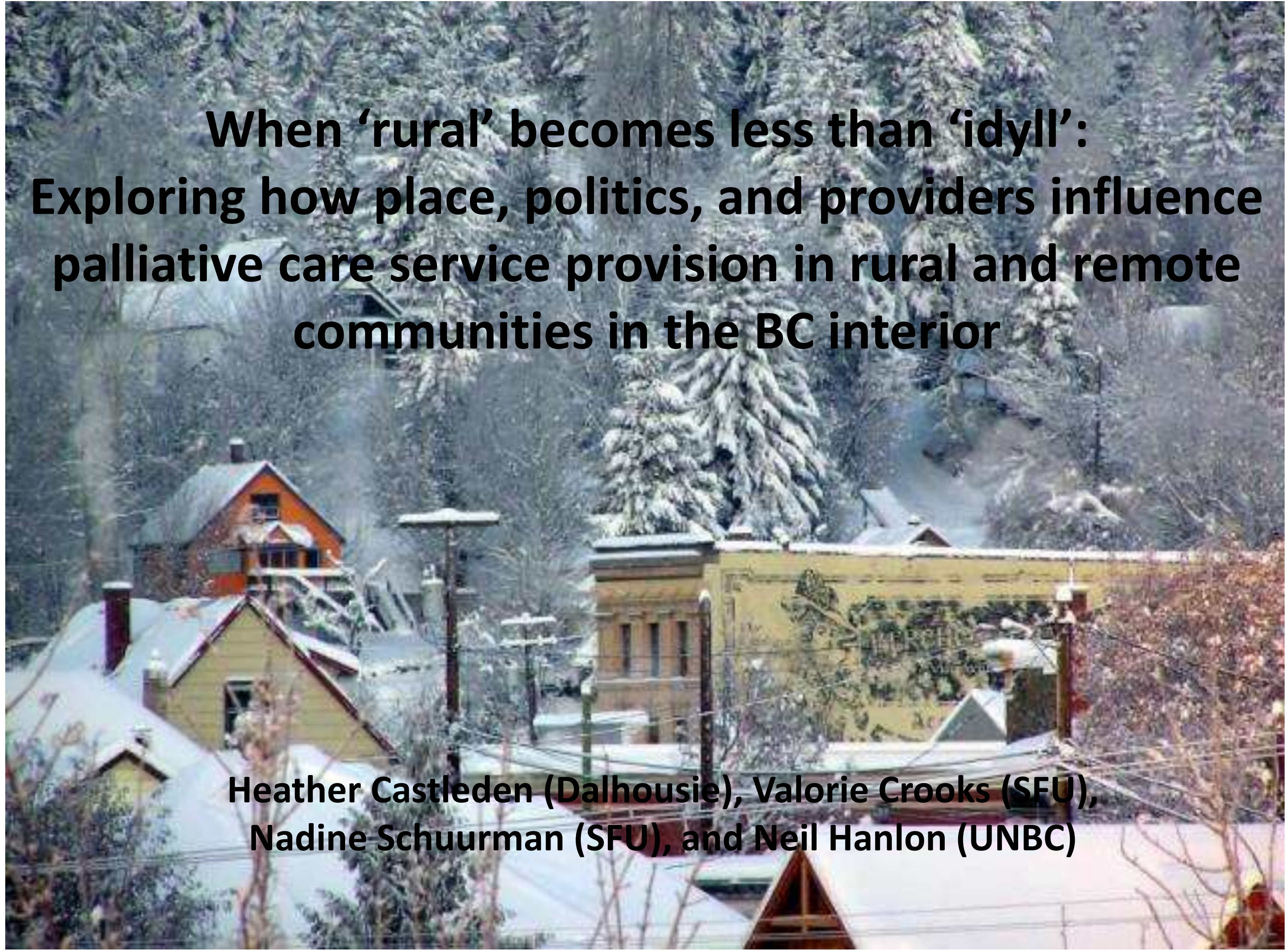
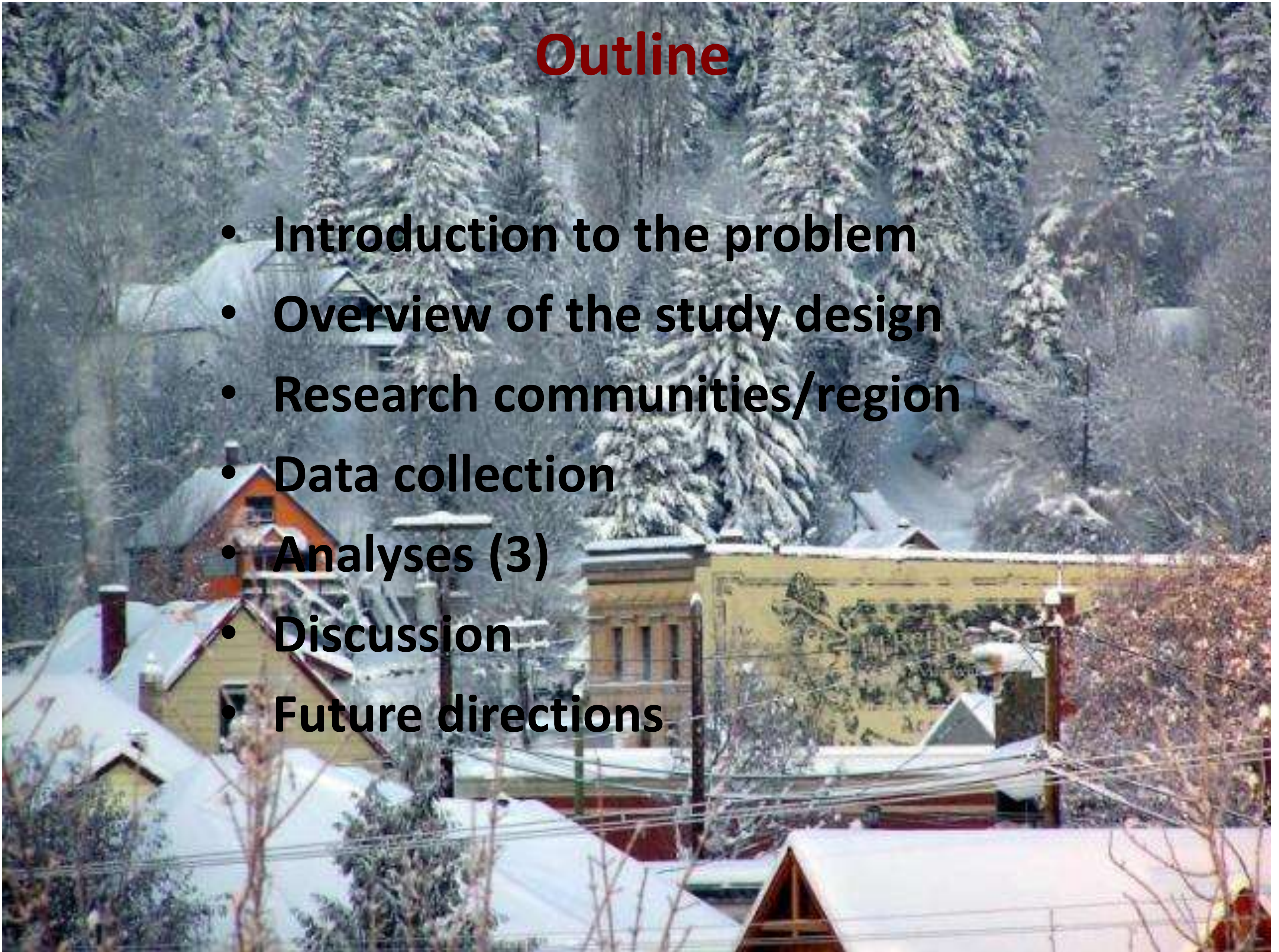
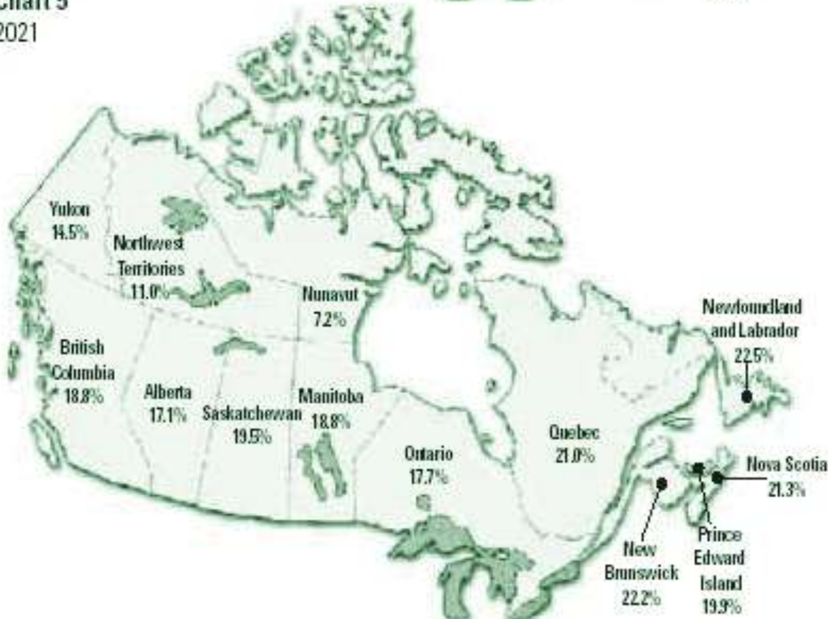
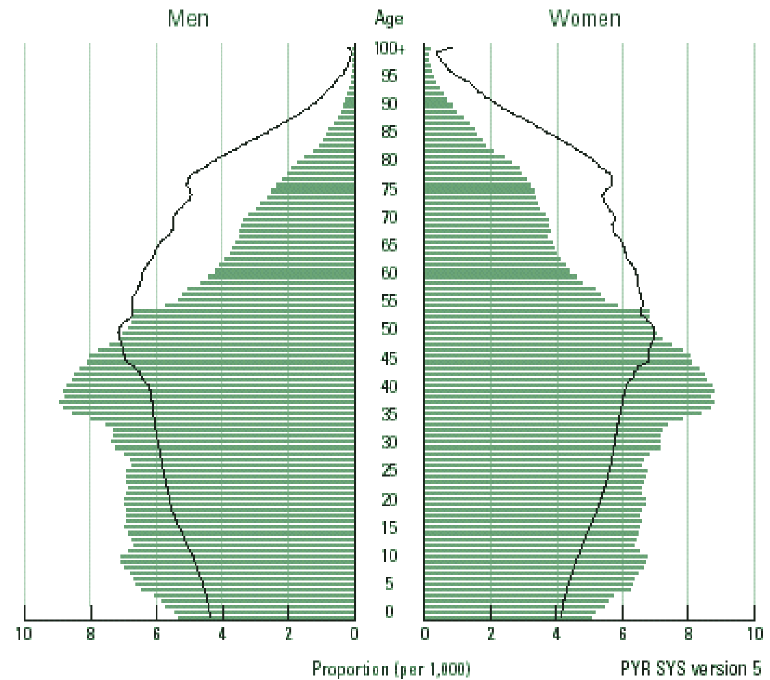


Copyright for this presentation belongs to the author. In all instances where this source is used it should be cited and the author contacted regarding copyright privileges.


Outline
• Introduction to the problem
• Overview of the study design
• Research communities/region
• Data collection
• Analyses (3)
• Discussion
• Future directions

The Problem





"With current estimates from Statistics Canada, the number of deaths is poised to increase 33% by the year 2020 and with current estimates of access to hospice palliative care services at approximately 15%, we are currently not ready for this stress on our health care system."

» *Canadian Hospice Palliative Care Association (2005)*

Charts from the Public Health Agency of Canada: http://www.phac-aspc.gc.ca/seniors-aines/publications/public/various-varies/papier-fed-paper/fedreport1-eng.php

- **The Study**
  - A mixed-method investigation into siting palliative care services in BC's interior region (Crooks & Schuurman, Co-PIs)

- **The Goal**
  - to take the first steps toward identifying those sites that are *most suitable* to serve as secondary palliative care hubs in rural and remote BC through undertaking a case study within the catchment of the IHA

- **The Objectives**

1. identify existing palliative care-rich and -poor sites in rural and remote BC

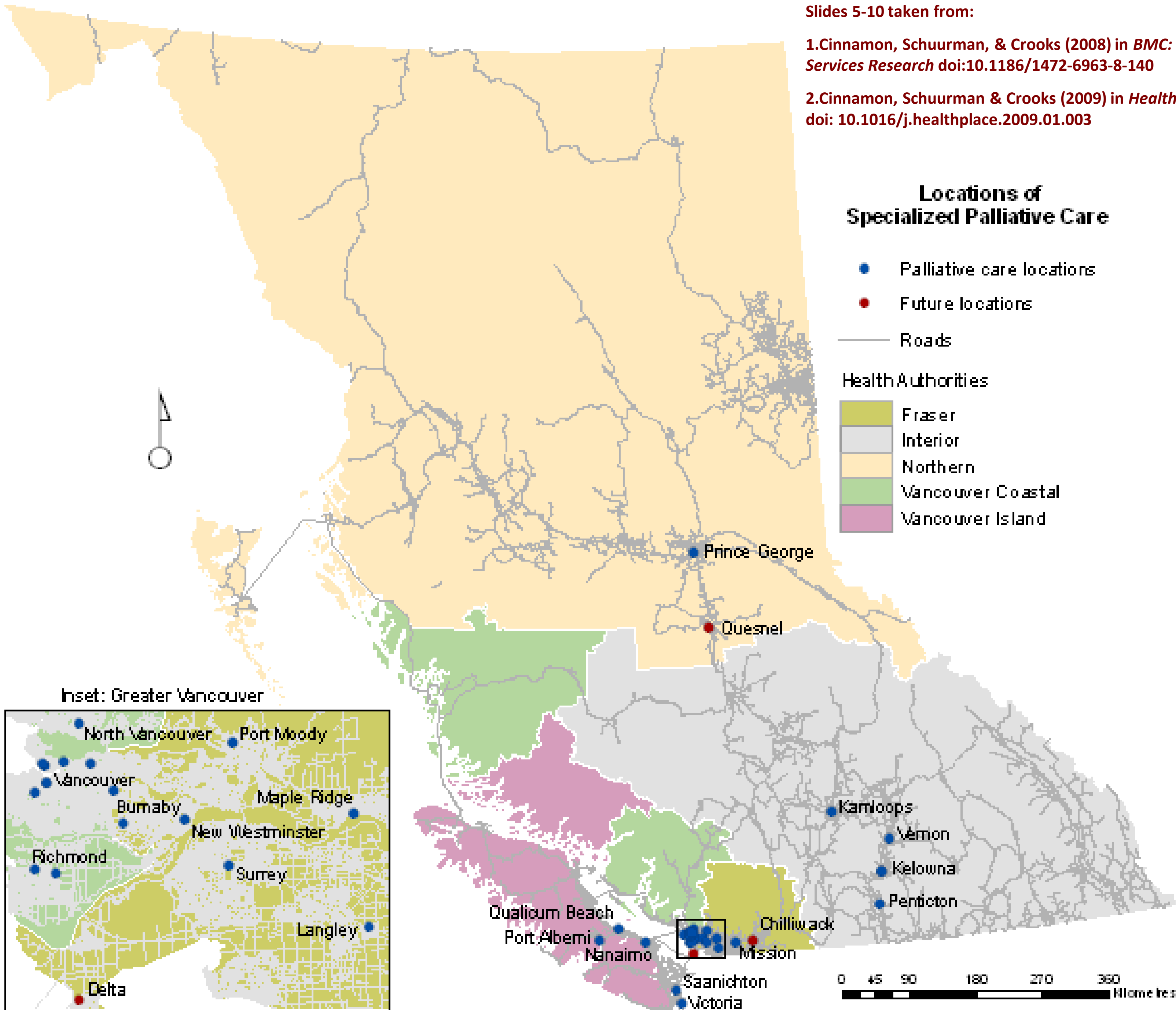
2. examine how barriers and facilitators to accessing palliative care are experienced in rural and remote BC and investigate how the establishment of secondary hubs is perceived by formal and informal service providers

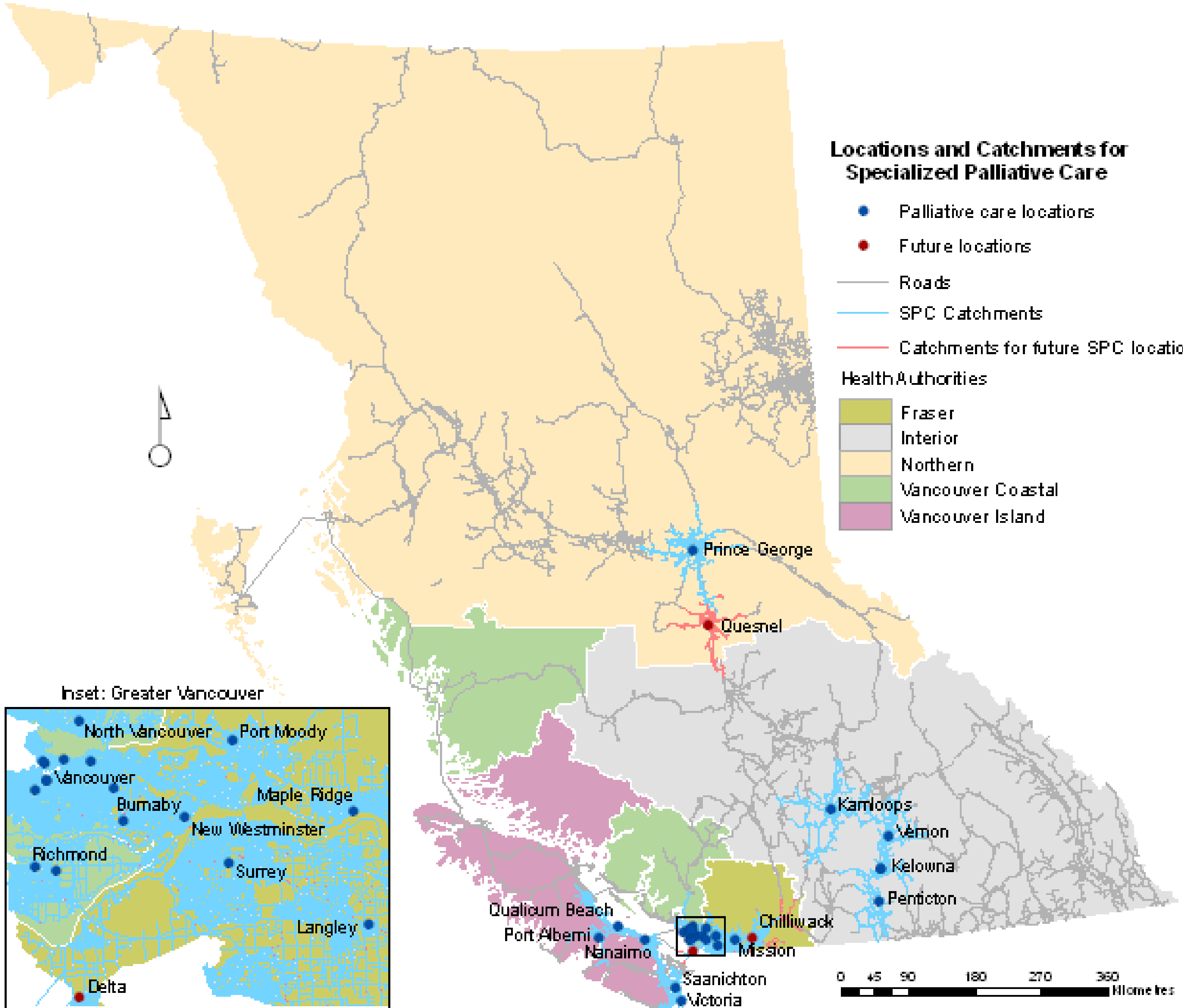
3. use the findings to determine which factors need to be considered in the development of a decision-support tool to inform the potential planning and development of secondary hubs

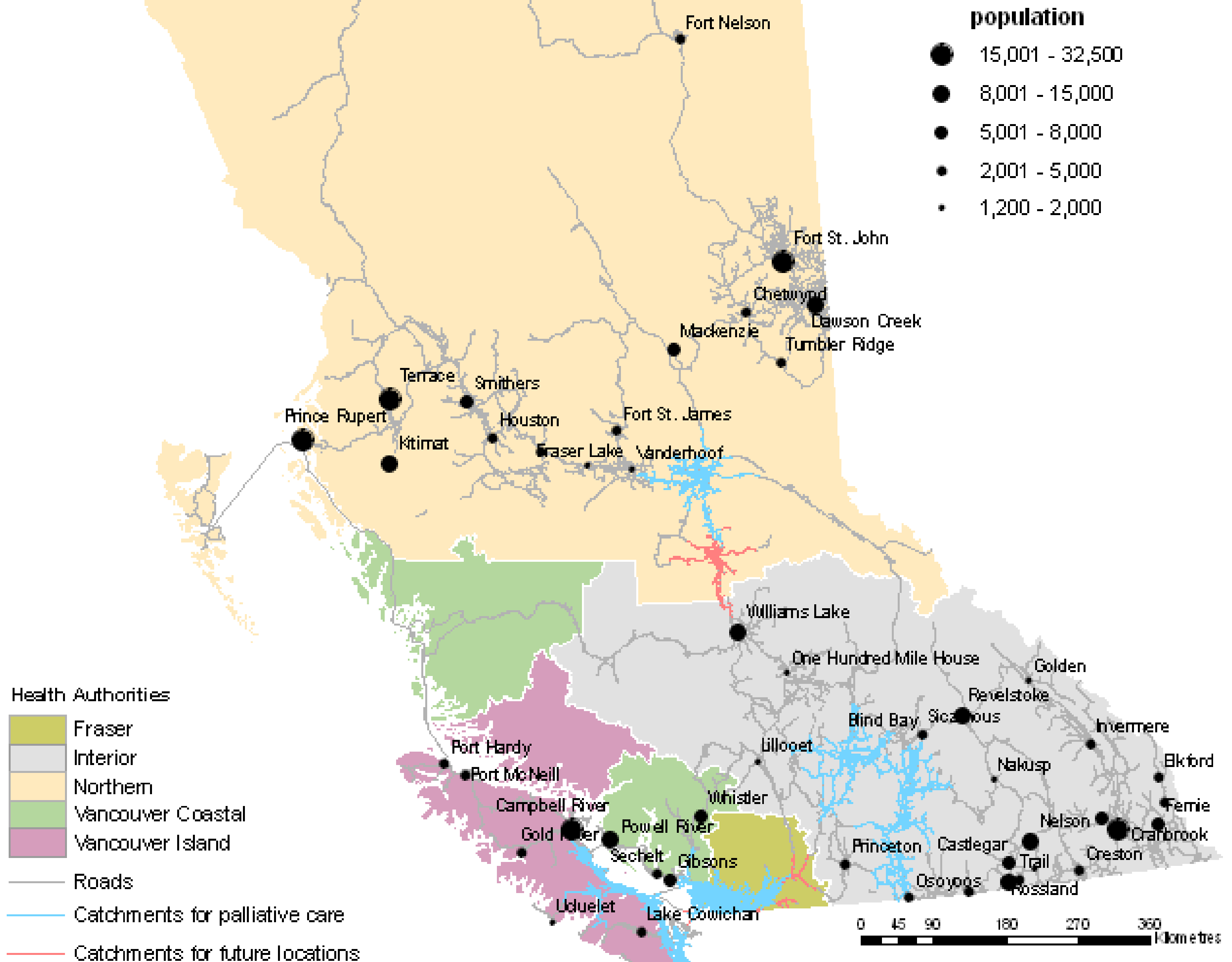
Slides 5-10 taken from:

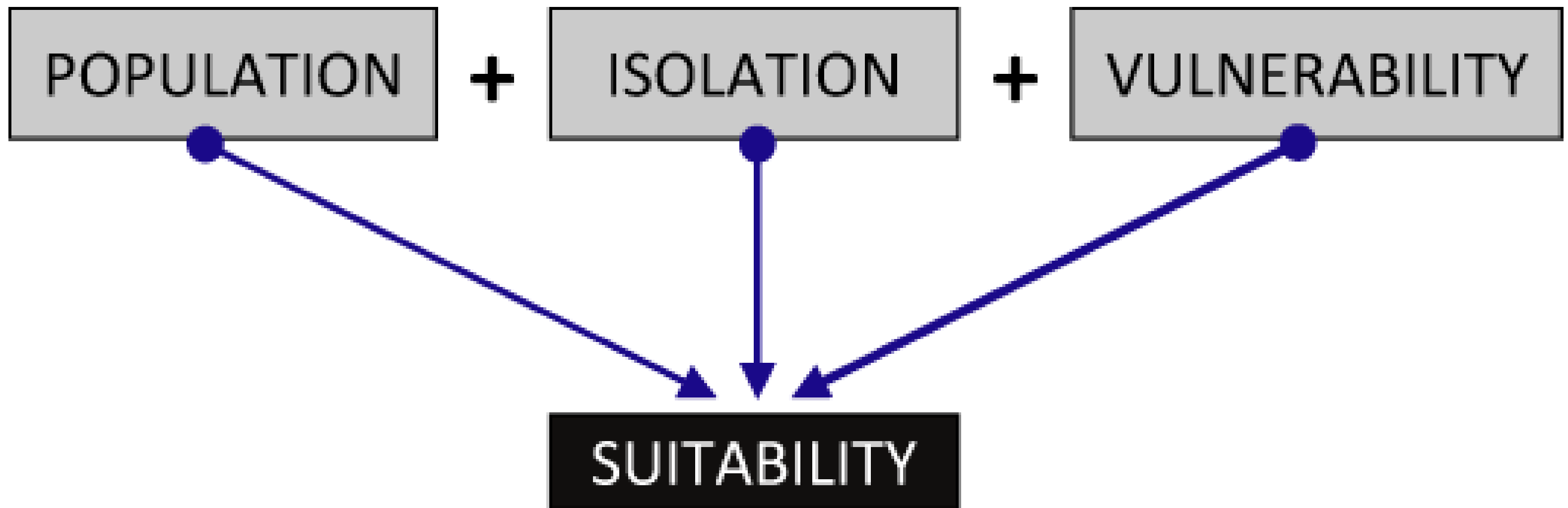
1.Cinnamon, Schuurman, & Crooks (2008) in *BMC: Health Services Research* doi:10.1186/1472-6963-8-140

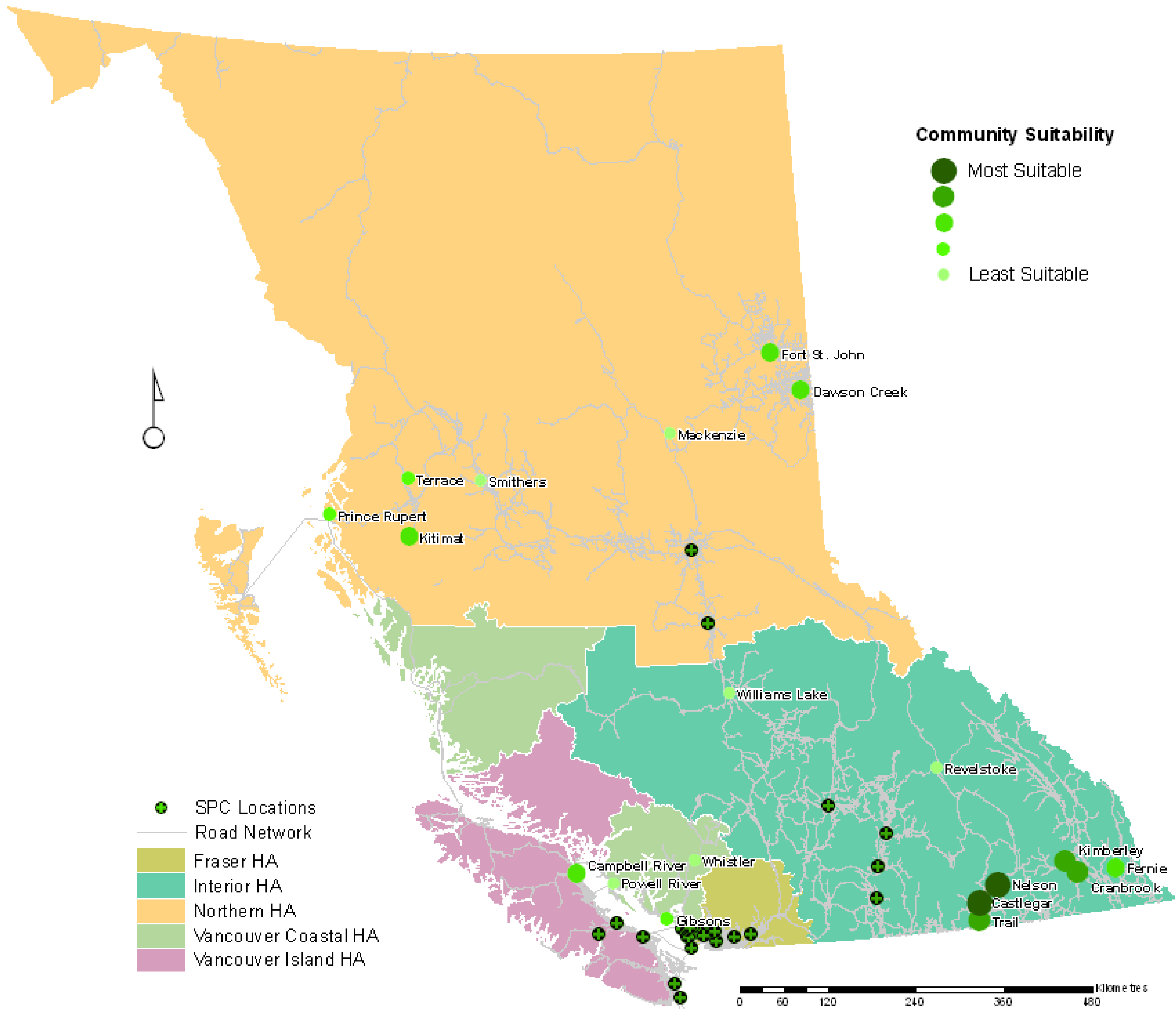
2.Cinnamon, Schuurman & Crooks (2009) in *Health & Place* doi: 10.1016/j.healthplace.2009.01.003




Locations and Catchments for Specialized Palliative Care
Palliative care locations
Future locations
Roads
SPC Catchments
Catchments for future SPC locations
Health Authorities
Fraser
Interior
Northern
Vancouver Coastal
Vancouver Island
Prince George
Quesnel
Kamloops
Vernon
Kelowna
Penticton
Chilliwack
Mission
Qualicum Beach
Port Alberni
Nanaimo
Saanichton
Victoria
0 45 90 180 270 360
Kilometres
Inset: Greater Vancouver
North Vancouver
Port Moody
Vancouver
Burnaby
Maple Ridge
New Westminster
Richmond
Surrey
Langley
Delta


Urban Areas More Than 1 Hour from Specialized Palliative Services
population
15,001 - 32,500
8,001 - 15,000
5,001 - 8,000
2,001 - 5,000
1,200 - 2,000
Fort Nelson
Fort St. John
Chetwynd
Dawson Creek
Mackenzie
Tumbler Ridge
Terrace
Smithers
Prince Rupert
Houston
Fort St. James
Kitimat
Fraser Lake
Vanderhoof
Williams Lake
One Hundred Mile House
Golden
Revelstoke
Blind Bay
Invermere
Lillooet
Nakusp
Elkford
Port Hardy
Port McNeill
Whistler
Fernie
Campbell River
Nelson
Powell River
Cranbrook
Princeton
Castlegar
Sechelt
Gibsons
Trail
Creston
Osoyoos
Rossland
Ucluelet
Lake Cowichan
Health Authorities
Fraser
Interior
Northern
Vancouver Coastal
Vancouver Island
Roads
Catchments for palliative care
Catchments for future locations
0 45 90 180 270 360
Kilometres


POPULATION
+
ISOLATION
+
VULNERABILITY
SUITABILITY

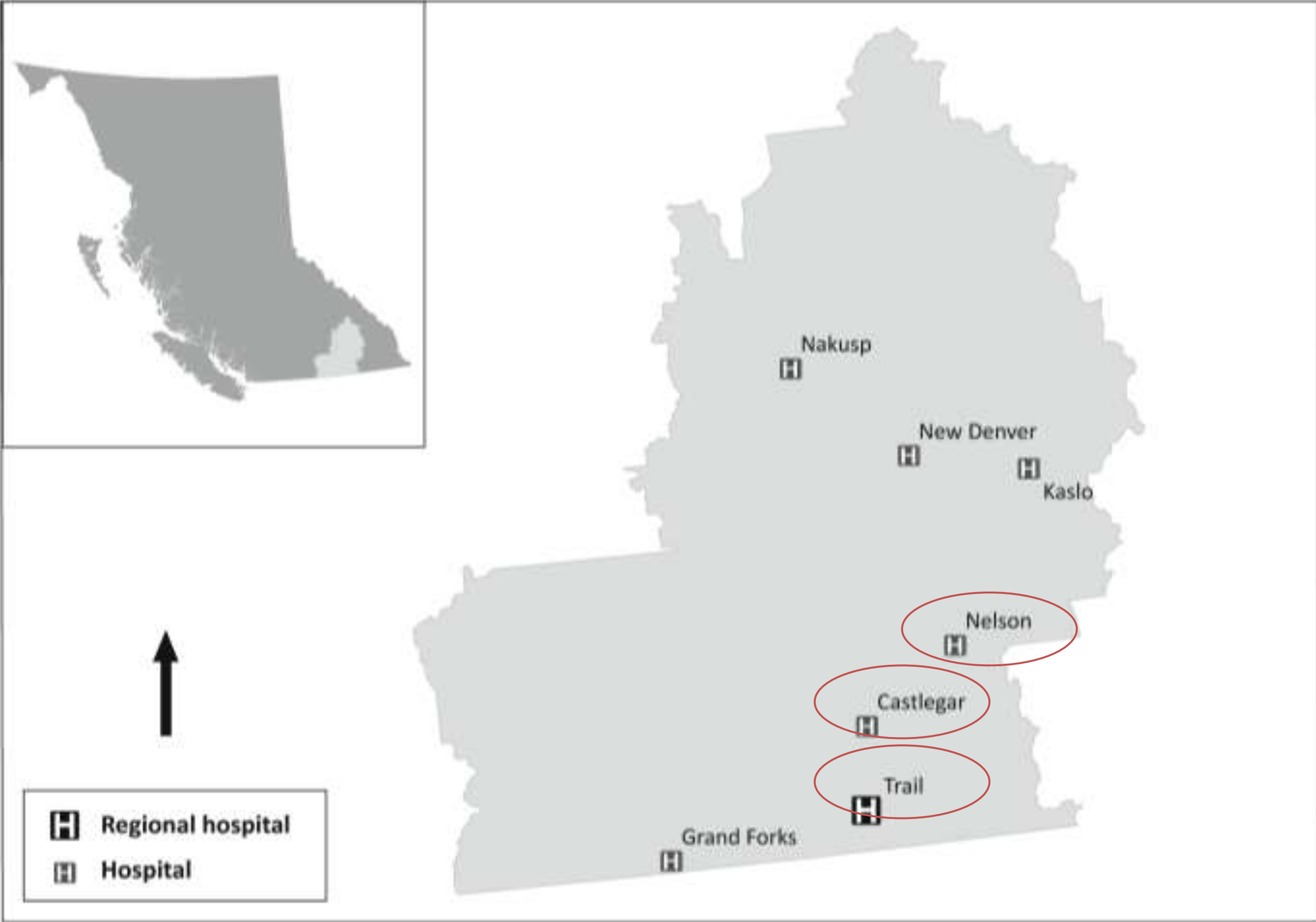


Community Suitability
Most Suitable
Least Suitable
Fort St. John
Dawson Creek
Mackenzie
Terrace
Smithers
Prince Rupert
Kitimat
Williams Lake
Revelstoke
Kimberley
Fernie
Nelson
Cranbrook
Castlegar
Trail
Campbell River
Whistler
Powell River
Gibsons
SPC Locations
Road Network
Fraser HA
Interior HA
Northern HA
Vancouver Coastal HA
Vancouver Island HA
0
60
120
240
360
480
Kilometres

Ranked List

Community	Health Authority	Rank
Nelson	**Interior**	**1**
Castlegar	**Interior**	**1**
Cranbrook	Interior	2
Trail	**Interior**	**3**
Kimberley	Interior	4
Campbell River	Vancouver Island	5
Fernie	Interior	5
Fort St. John	Northern	5
Dawson Creek	Northern	6
Kitimat	Northern	7
Terrace	Northern	8
Gibsons	Vancouver Coastal	9
Prince Rupert	Northern	10
Powell River	Vancouver Coastal	11
Smithers	Northern	12
Revelstoke	Interior	13
Whistler	Vancouver Coastal	13
Williams Lake	Interior	13
Mackenzie	Northern	14

Case Study: West Kootenay-Boundary Region



Interview Overview (N=31)

PROBES

- Community health & health care priorities and challenges
- Community need for palliative care & existing availability
- Community palliative care challenges
- Secondary hub approach

Role/Occupational Group	Number
Nursing	7
Health care administrator	6
Hospice/palliative care volunteer	5
Other	4
Family doctor	2
Pastor/minister	2
Hospice society worker	2
Allied health care professional	2
Family caregiver	1

Analyses (3)

1. Place as an analytic tool for rural palliative care
   - Distance, location, aesthetics, sites of care

2. Politics of rural palliative care
   - Inter-community, inter-site, inter-professional

3. Providers' perceptions of rural Aboriginal palliative care
   - In/visibility, contradictions, necessary elements

Analysis 1: ‘It’s not necessarily the distance on the map…’: Using place as an analytic tool to elucidate geographic issues central to rural palliative care

1. Physical place
   - *Connotations of place as a material artefact, a literal location, and/or a setting for social relations*

2. Social place
   - *People give meanings to places, engage in place-making activities, understand their place in social hierarchies, develop a sense of place, and create emotional attachments to places*

Castleden, Crooks, Hanlon, & Schuurman (In Press) *Health & Place*

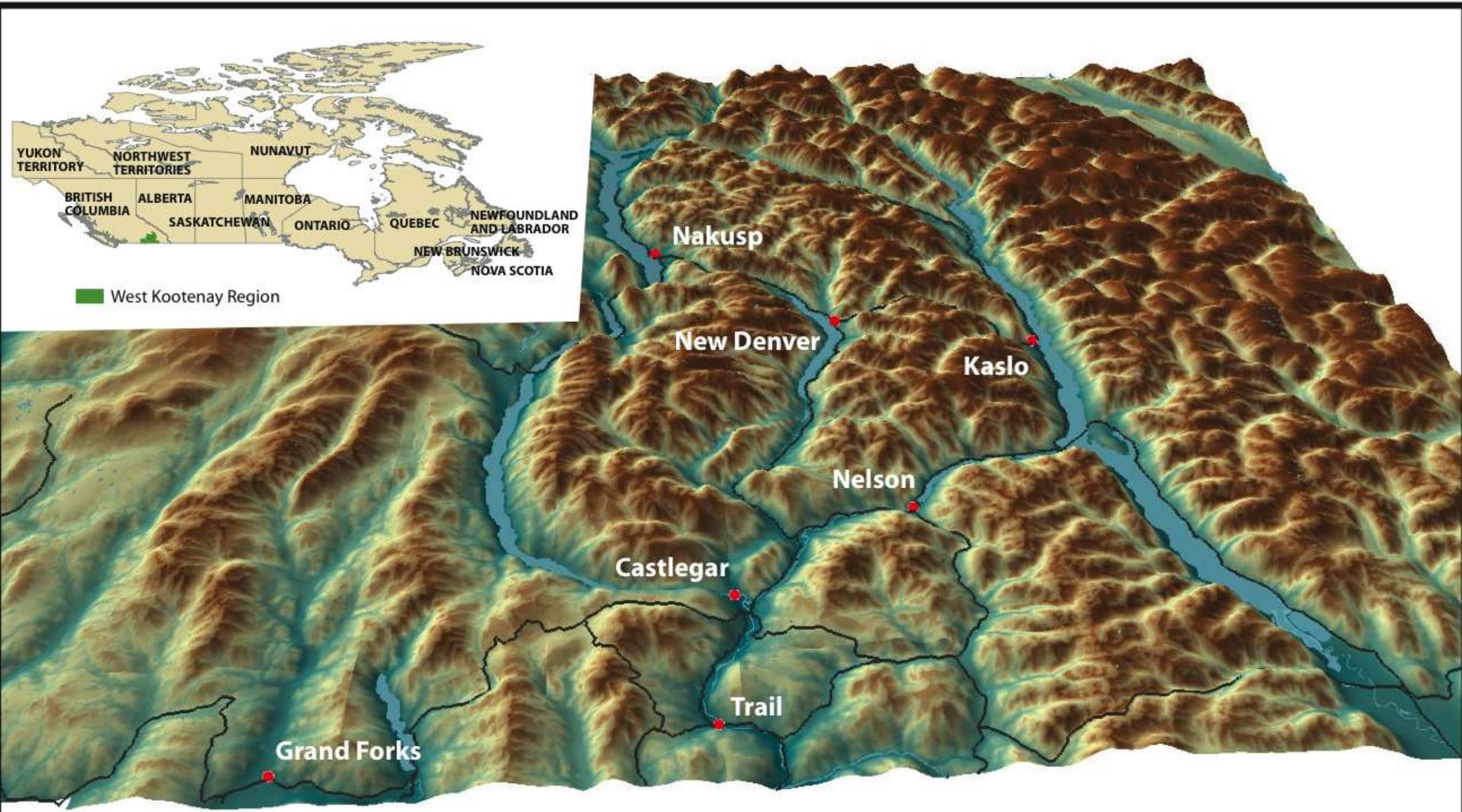
	SPATIAL DISTANCE:	MOUNTAINOUS LOCATION:	PLACE AESTHETICS:	LITERAL SITES OF CARE:
The Physical Place of Rural Palliative Care	*It's not necessarily the distance on the map, it is the actual…reality of the roads.* *It's a long way to go [to the regional hospital], it's a half and hour, which is a long way here. I know for the city it isn't.*	*Decision makers should take a drive through the interior, and preferably in January, and get a sense of the distances involved, the mountain passes, and the snow conditions.*	*I'm not satisfied with the rooms at all. The care [and] the nurses are fine, but it's pretty awful to be going to such a barren room, and those are your last days.*	Participants' collective vision for palliative care included offering choice regarding the site of care and providing an environment that allows for *being able to live through the dying process.*
	DISTANCE PERCEPTIONS:	**SOCIAL LOCATIONS:**	**CREATING A SOCIAL AESTHETIC:**	**SITES OF CONTROL IN CARE:**
The Social Place of Rural Palliative Care	*Every time you leave town, it costs and, you know, you have to stay overnight and you have to eat and you use the phone to phone your family and so you're accruing phone bills.*	*The politics of the Kootenay Boundary are quite unique to the province…none of the communities get along very well.*	*When you read the 'obits', you'll often find that line in it, that says 'he died surround by friends and family' and it is so important for the family to be able to say 'we were there'.*	*…I'm thinking of the care professionals for whom it is intensely difficult to move from an acute care situation into a palliative care situation, and then back again within minutes…*

The 'first available bed' works on the coast, not out here…

- Fanny and Al Albo
- Married for 70+ years
- First available bed policy in BC = transfer to long-term care facility more than 100 km away
- Fanny died the day after she was separated from her husband
- Her death sparked an investigation by BC's Deputy Health Minister
- Findings: Fanny Albo did not get quality care

http://www.cbc.ca/canada/british-columbia/story/2006/03/02/bc_al-albo20060302.html

Implications



Analysis 2: The politics of rural palliative care delivery: A case study from British Columbia, Canada

- Rural palliative care is provided by multiple professionals and informal providers across a range of settings
- Such diversity is a strength and challenge

- **In this analysis we asked:**

  Who has the power to decide: (1) Where palliative care is provided; (2) Whether palliative care is provided; and (3) How palliative care is provided?

- **Objectives**
- (1) articulate the different levels of politics at play; (2) identify themes that crosscut the politics at play; and (3) consider the implications of the results for rural palliative care practice and delivery

Crooks, Castleden, Hanlon, & Schuurman (In Preparation) *Journal of Palliative Medicine*

The Politics of Palliative Care	**Inter-community**	**Inter-site**	**Inter-professional**
Ownership	*The problem is, in the Kootenays, there's always a huge discussion about where things should be in terms of medicine and they've mostly ended up in Trail.*	*There is a committee that meets and provides services, particularly to the beds that are in [the X] Lodge, that decides who can go there. So there's a couple of physicians that have a specialty interest. There's a lot of politics that goes on.*	*Historically in our area many of the local physicians, have been opposed to… having a person that they could go to because they just wanted to look after their own patients.*
Entitlement	*If the [RHA] was to say that [a new service was] going to be in Trail, which is the most likely place that they would put it - because that's where the regional hospital, because Cominco [mining company] has a huge political power pull there - Nelson would just go, "Oh well… that's the way it's always been.*	*If people want to palliate at home we should do everything we can to keep them there. Unfortunately it's very difficult in this area to keep people at home because we don't have enough [home care] services to keep them at home. So it's kind of like mixed messages, we want to keep them at home, that's [the NHA] goal, but we just don't have enough resources to actually do that.*	*I think the home care nurses were threatened. They didn't like somebody coming in and telling them, you know, how to do pain and symptom management. They felt like they had enough expertise.*
Administration	*I think [the RHA] sometimes tends to impose things on areas, and that's not always well accepted. I think we would do much better if we could work from the grass roots up and develop something that was a little bit more of a "one size fit everybody". It's not going to be perfect for anybody, but everybody has some investment in it.*	*Well, I think you'd probably have to go to the RHA to find out about [why they chose Trail for the regional hospital] because their decision was certainly beyond anything that we had ever imagined here and it made no sense to anyone in the region because we have this beautiful facility here [in Castlegar].*	*There has to stop being a dividing line between the acute, residential, and community care budgets. However we fund it, it has to be out of a shared pot, because palliative care happens in all those areas and so to say, "This is mine, and this is mine, and this is mine." is what fragments it. And then nobody wins, and nobody has enough resources.*

YUKON TERRITORY
NORTHWEST TERRITORIES
NUNAVUT
BRITISH COLUMBIA
ALBERTA
MANITOBA
SASKATCHEWAN
ONTARIO
QUEBEC
NEWFOUNDLAND AND LABRADOR
NEW BRUNSWICK
NOVA SCOTIA
West Kootenay Region
Nakusp
New Denver
Kaslo
Nelson
Castlegar
Trail
Grand Forks

The Politics of Palliative Care	**Inter-community**	**Inter-site**	**Inter-professional**
Ownership	*The problem is, in the Kootenays, there's always a huge discussion about where things should be in terms of medicine and they've mostly ended up in Trail.*	*There is a committee that meets and provides services, particularly to the beds that are in [the X] Lodge, that decides who can go there. So there's a couple of physicians that have a specialty interest. There's a lot of politics that goes on.*	*Historically in our area many of the local physicians, have been opposed to… having a person that they could go to because they just wanted to look after their own patients.*
Entitlement	*If the [RHA] was to say that [a new service was] going to be in Trail, which is the most likely place that they would put it - because that's where the regional hospital, because Cominco [mining company] has a huge political power pull there - Nelson would just go, "Oh well… that's the way it's always been.*	*If people want to palliate at home we should do everything we can to keep them there. Unfortunately it's very difficult in this area to keep people at home because we don't have enough [home care] services to keep them at home. So it's kind of like mixed messages, we want to keep them at home, that's [the NHA] goal, but we just don't have enough resources to actually do that.*	*I think the home care nurses were threatened. They didn't like somebody coming in and telling them, you know, how to do pain and symptom management. They felt like they had enough expertise.*
Administration	*I think [the RHA] sometimes tends to impose things on areas, and that's not always well accepted. I think we would do much better if we could work from the grass roots up and develop something that was a little bit more of a "one size fit everybody". It's not going to be perfect for anybody, but everybody has some investment in it.*	*Well, I think you'd probably have to go to the RHA to find out about [why they chose Trail for the regional hospital] because their decision was certainly beyond anything that we had ever imagined here and it made no sense to anyone in the region because we have this beautiful facility here [in Castlegar].*	*There has to stop being a dividing line between the acute, residential, and community care budgets. However we fund it, it has to be out of a shared pot, because palliative care happens in all those areas and so to say, "This is mine, and this is mine, and this is mine." is what fragments it. And then nobody wins, and nobody has enough resources.*

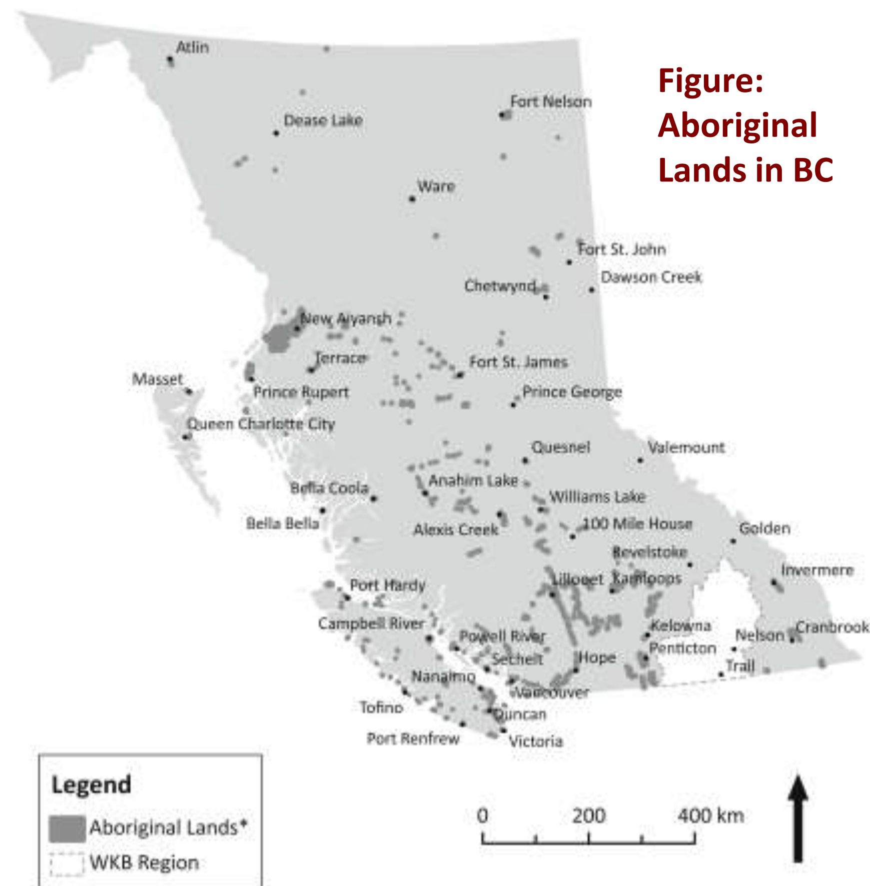
Implications

Politics across communities, sites, and professionals simultaneously facilitate and block quality palliative care provision.

- Facilitators:
  - Assume advocacy roles
  - Raise awareness
  - Increase attention on system navigation challenges
  - Ultimately facilitate client access to care
- Barriers
  - Resources are not equitably divided
  - Vocal groups gain more
  - Impact clients and families by limiting choice
  - Fracture relationships between groups

Analysis 3: "I see mostly white faces...[Aboriginal people] take care of their own": Providers' perceptions of Aboriginal palliative care in British Columbia's rural interior

- Aboriginal peoples and the Canadian healthcare system
  - Disproportionate burden of ill health
  - History of racism in the health system
- Growing Aboriginal population
- Aboriginal health
  - enhancing quality of care from birth to death



*Aboriginal lands consist of all census subdivisions (CSD) legally affiliated with First Nations or Indian Bands. There are 5 aboriginal CSD types in British Columbia: Indian reserve (IRI), Indian government district (IGD), Nisga'a land (NL), Nisga'a village (NVL), Indian settlement (S-É)

Castleden, Crooks, Hanlon, & Schuurman (In Review) *Health & Social Care in the Community*

Providers' Perceptions: Aboriginal Palliative Care

Visibility	*[The region] would be mostly, I'm going to say, white Anglo Saxon communities. There's very few black or darker skinned, Afro-American people, very few, like, Oriental or Asian people…you know, fairly mono-cultural.*	*The original [Aboriginal] group that was here, the Sinixt, were declared extinct.* *MAP*	*There's [Aboriginal] people that are lighter skinned, and they are...like half. There's a whole large group that are half, intermix or whatever. So I can't identify them.*
Contradictions	*When [you're] going as a hospice worker you don't have any prejudice – I don't and nobody does – about their culture and religion.* --- *A patient was racially attacked and the physician was using terminology, 'You people are always'… and using [an] elevated voice to… ensure that they're heard, and the patient left with little dignity... That [Aboriginal patient] requires regular contact with health services, and is now feeling very, very distrustful, and scared to receive and access, and even enter the building.*	*[Aboriginal people] go back where they came from… I've seen it happen…where the services become increasingly difficult to access, and they just they return to the place familiar to them and usually it's back where they came from…we don't keep them here... there's definitely a pattern.* -- *Some who have been associated with a reserve will go back, but most don't.*	*The traditional Canadian family [is] probably more receptive to palliative care services than some of your more ethnic minority groups are.* -- *I think they're getting more tuned to what their past spiritual practices were and so I think that's helpful. You know, like they now do smudging and all that sort of thing which I don't think they did in the past, or certainly not that we knew of.*
Necessary Elements	Training *Do we culturally understand the differences in the way people approach death? I'm not sure any of us have had, in this area, very much training or exploration of that*	Location *[It is] very important that palliative areas… physically look non-threatening or [as] least institutionalized as possible just because of the residential school experience…and to end your life in a building that may look like that could, you know, really trigger some emotional stuff.*	Resources *•Close proximity to natural surroundings* *•Ability to practice ceremonial activities* *•Access to traditional foods* *•Use of traditional medicines*

Aboriginal Lands in BC

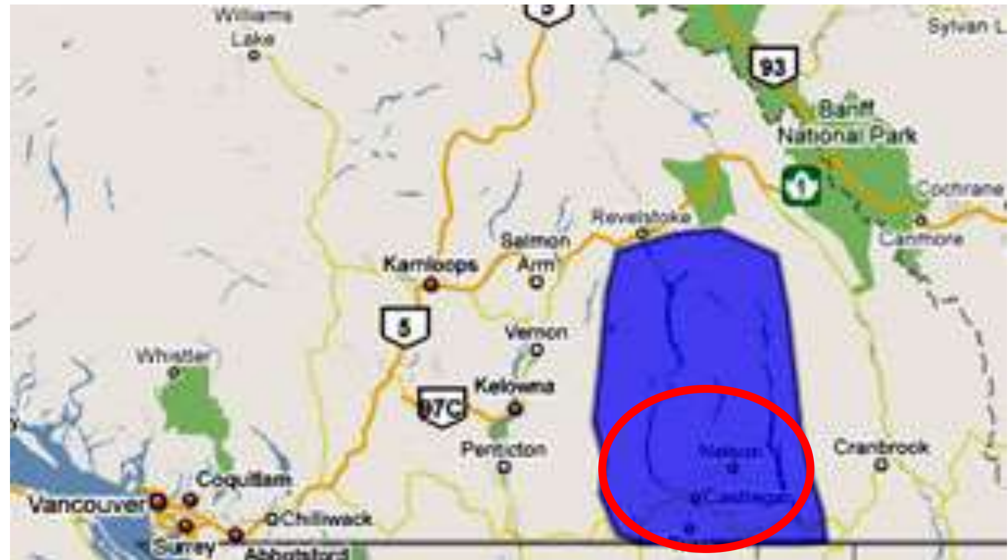
Bella Coola
Williams Lake
Bella Bella
Alexis Creek
100 Mile House
Golden
Revelstoke
Invermere
Port Hardy
Lillooet
Kamloops
Campbell River
Kelowna
Nelson
Cranbrook
Powell River
Penticton
Sechelt
Hope
Trail
Nanaimo
Vancouver
Tofino
Duncan
Port Renfrew
Victoria

Legend

Aboriginal Lands*

WKB Region

Sinixt Land Claim Area



http://www.cbc.ca/aboriginal/images-blog/bc-080801-sinixt-landclaim1.jpg

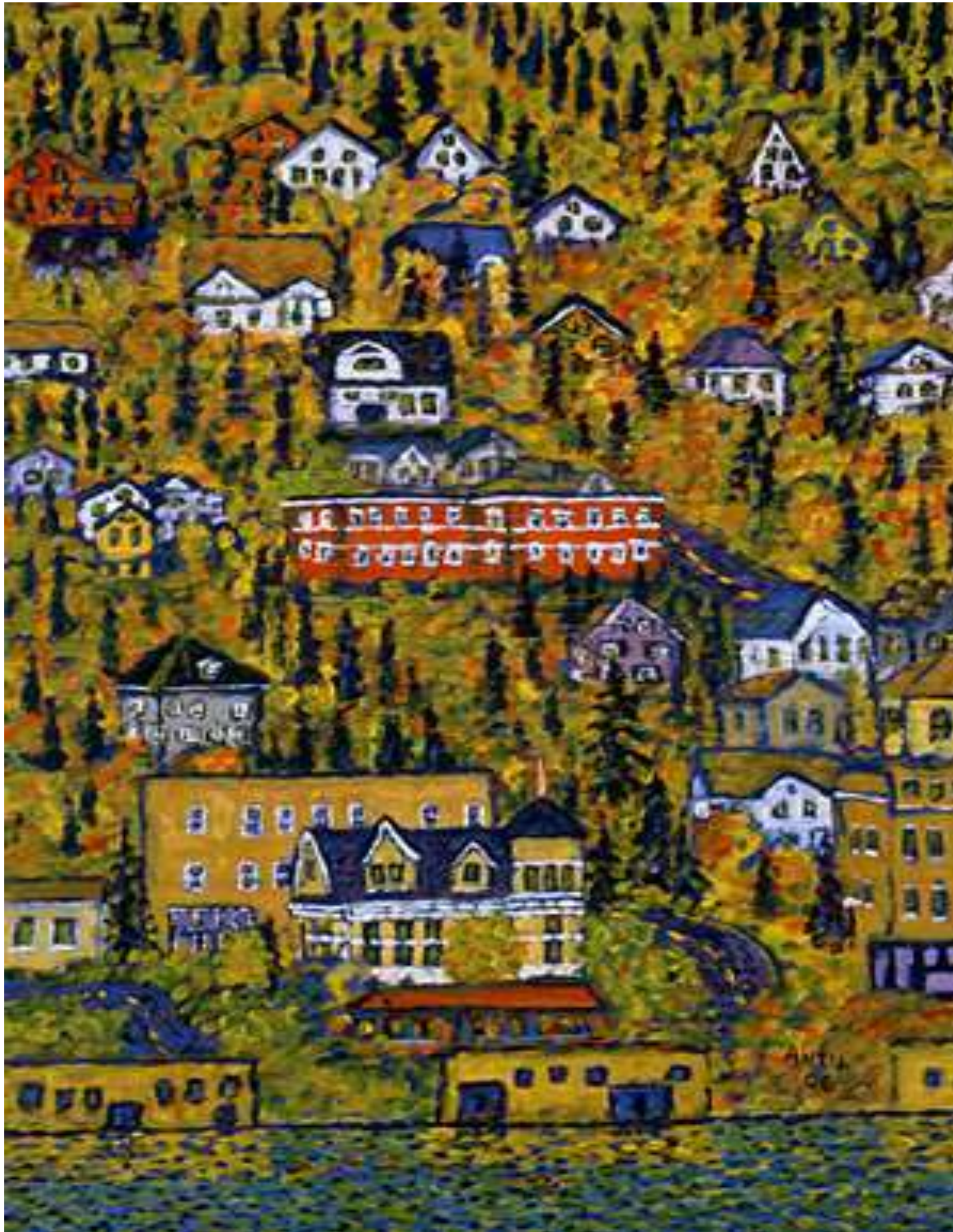
Providers' Perceptions: Aboriginal Palliative Care

Visibility	*[The region] would be mostly, I'm going to say, white Anglo Saxon communities. There's very few black or darker skinned, Afro-American people, very few, like, Oriental or Asian people…you know, fairly mono-cultural.*	*The original [Aboriginal] group that was here, the Sinixt, were declared extinct.*	*There's [Aboriginal] people that are lighter skinned, and they are...like half. There's a whole large group that are half, intermix or whatever. So I can't identify them.*
Contradictions	*When [you're] going as a hospice worker you don't have any prejudice – I don't and nobody does – about their culture and religion.* -- *A patient was racially attacked and the physician was using terminology, 'You people are always'… and using [an] elevated voice to… ensure that they're heard, and the patient left with little dignity... That [Aboriginal patient]… is now feeling very, very distrustful, and scared to… even enter the building.*	*[Aboriginal people] go back where they came from… I've seen it happen…where the services become increasingly difficult to access, and they just they return to the place familiar to them and usually it's back where they came from…we don't keep them here... there's definitely a pattern.* -- *Some who have been associated with a reserve will go back, but most don't.*	*The traditional Canadian family [is] probably more receptive to palliative care services than some of your more ethnic minority groups are.* -- *I think they're getting more tuned to what their past spiritual practices were and so I think that's helpful… Like they now do smudging and all that sort of thing which I don't think they did in the past, or certainly not that we knew of.*
Necessary Elements	**Training** *Do we culturally understand the differences in the way people approach death? I'm not sure any of us have had, in this area, very much training or exploration of that*	**Location** *[It is] very important that palliative areas… physically look non-threatening or [as] least institutionalized as possible just because of the residential school experience…and to end your life in a building that may look like that could, you know, really trigger some emotional stuff.*	**Resources** *•Close proximity to natural surroundings* *•Ability to practice ceremonial activities* *•Access to traditional foods* *•Use of traditional medicines*

Implications

- Culture matters in the provision of palliative care
- Rurality and population size matters
- Rural care providers are resourceful and resilient
- Professional development opportunities are needed/desired
- Seek direction from minority cultural groups for ways to provide culturally sensitive palliative care.
- Additional studies needed to create better living and dying conditions for the descendents of Canada's original inhabitants.

Concluding Comments



http://www.tomantilart.com/images/landscapes/Nelson_BC.jpg

Concluding Comments

http://www.mountainwatersretreats.ca/images/glunsnewyorker105.jpg

Acknowledgements

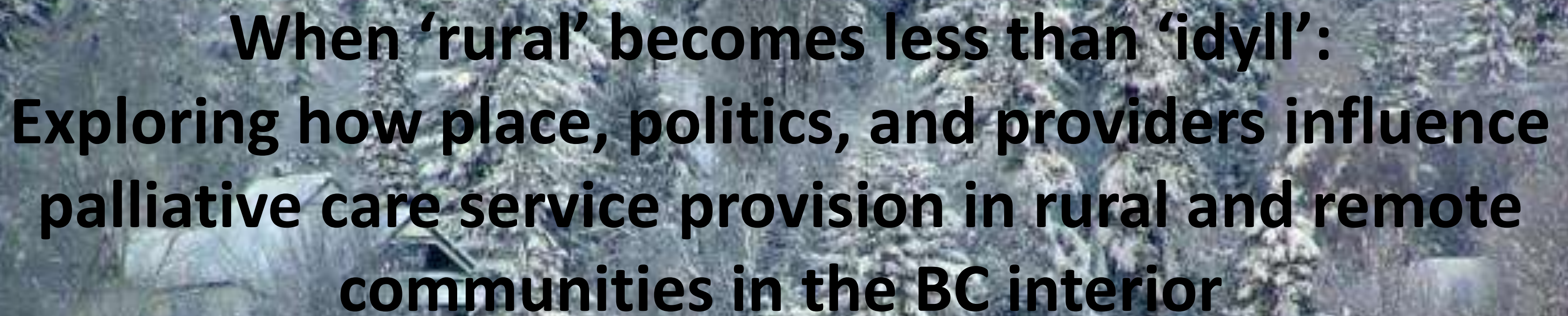
Participants

VANCOUVER FOUNDATION

Co-authors

Future Directions: CIHR Catalyst on Health Equity

NELS | Network for End of Life Studies



When ‘rural’ becomes less than ‘idyll’: Exploring how place, politics, and providers influence palliative care service provision in rural and remote communities in the BC interior

Heather Castleden (Dalhousie), Valorie Crooks (SFU), Nadine Schuurman (SFU), and Neil Hanlon (UNBC)

http://www.canadapondhockey.ca/ezweb/images/upload/nov28town2_preview.jpg