

Walking in Two Worlds: Hepatitis C Advocacy Resources for Canada's Inuit

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Background

Hepatitis C is a complex health condition that requires ongoing management over the person's lifetime. People living with hepatitis C have reported challenges with misinformation about treatment options and difficulty obtaining reliable advice and support.

In partnership with the federal government, the BCCDC is working to develop a national package of educational material designed to help people living with hepatitis C successfully navigate health and social care systems in order to improve their self-care. This tool has been tailored to the English, French, and Aboriginal populations in Canada. Upon review of the Aboriginal booklet, Aboriginal affiliates recommended adapting the information to meet the needs of the Inuit population.

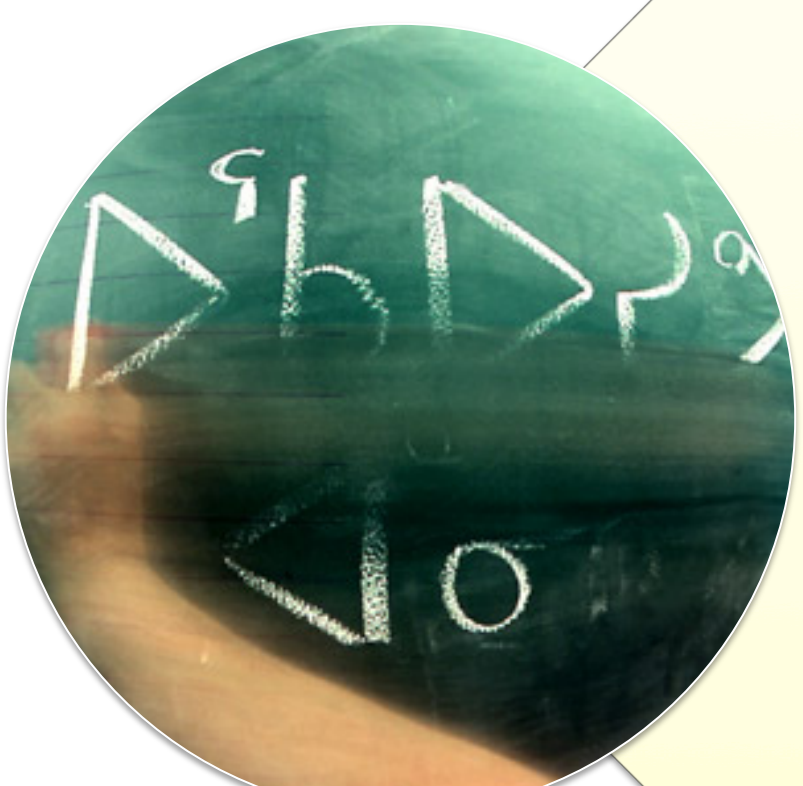
Canada's Inuit possess a unique culture and learning style and are in need of a booklet that is culturally sensitive and reflective of this uniqueness. They also face unique geographical and resource challenges when accessing health care services.

Learning & Literacy



Traditional Learning Styles

Knowledge was passed on orally by those who had more experience and skills, through stories, songs and legends
Skills were learned mainly by observation and hands-on practice
Appropriate social behaviour was learned through oral feedback and observation of behaviour and consequences
Teaching was done by example, demonstration and storytelling
The Inuit emphasize that learning is individual, holistic, and experiential



Literacy

We need to consider the best way to disseminate this self-advocacy training to the Inuit people. A report by Stats Canada in 2005 showed:
47% of Inuit report difficulty reading and writing in their native languages (Inuktitut/Inuinnaqtun)
English/French are often second languages for the Inuit
According to the International Adult Literacy & Skill Survey, 88% of Inuit scored at a literacy level that "makes it difficult to meet the challenges of today's society"
After reviewing this information, we questioned whether the workbooks alone were going to be an effective way to move forward with this project.
How can we effectively incorporate technology?
Suggestions: MP3 players, Interactive Video, Internet access

Case Studies

Nukka was diagnosed with hepatitis C several years ago. She is genotype 1 and in the past has been asymptomatic. Recently, she has been suffering from many of the symptoms associated with chronic hepatitis C. The traveling physician that visits her community once a month has recommended that she have a liver biopsy. In order for her to have this test she needs to leave her community and fly to an urban hospital. The plane she needs to take only flies in and out of her community once a week so she will have to spend a week away from her family and community.

- What obstacles is Nukka facing?
- What questions should she ask her doctor about the procedure?
- What resources are available to her in the city?

Nukka's English is limited. She is scared about the procedure and does not want to travel alone. She would like to bring a family member with her for support and strength but the health authority will only pay for her flight.

- What are Nukka's obstacles?
- How can she overcome these obstacles?
- Who should she involve to help her?
- What other resources are available to her?

Unique Challenges

When making modifications to the case studies, we tried to reflect the unique challenges this population might face. We wanted the reader to be able to identify with the situations.

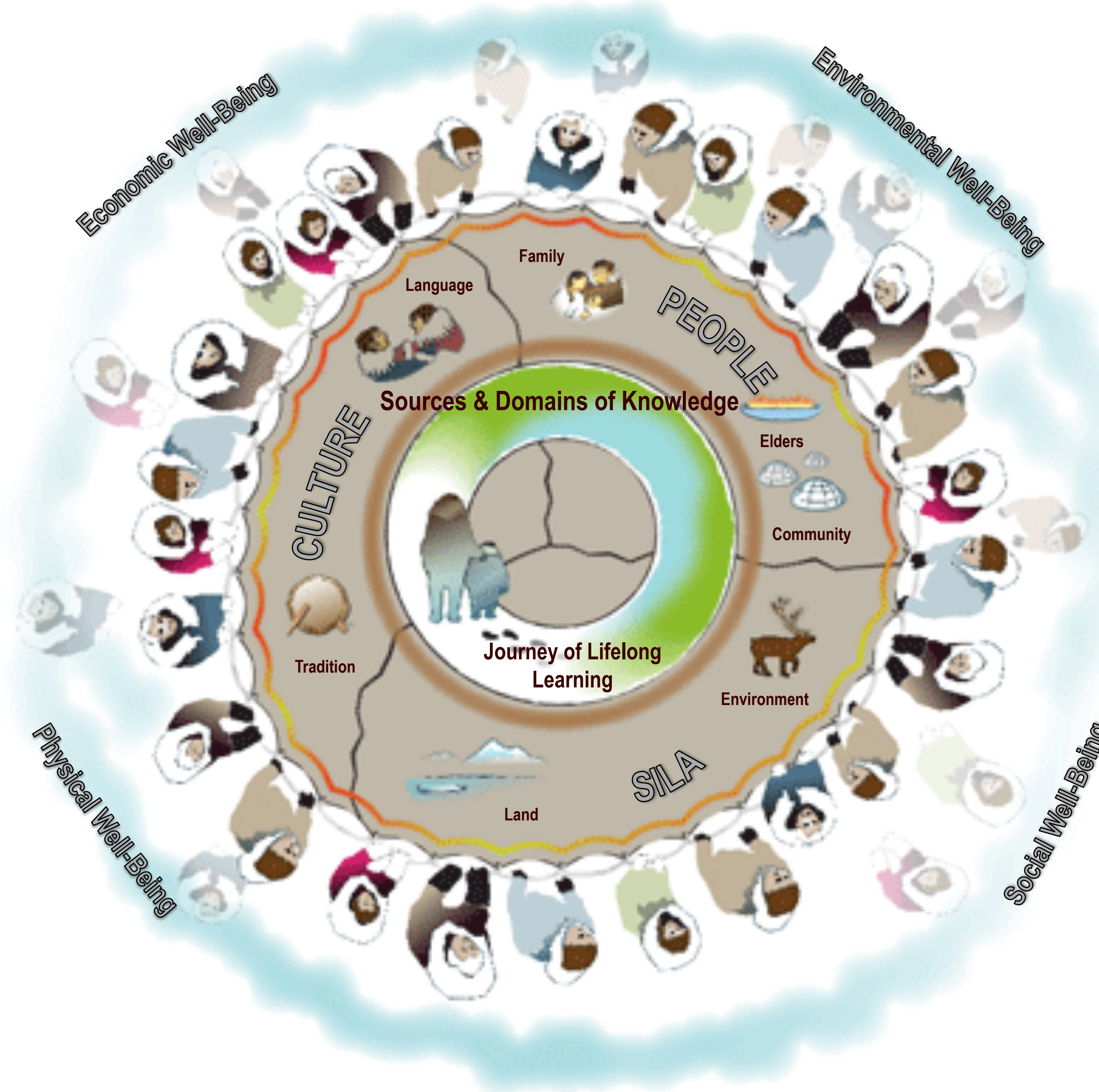
- Most communities are fly-in only, with limited service
- In smaller communities, health services are provided by nurses, with visiting doctors
- English is often a 2nd language
- Funding is often not available to fly support people with patients

Project Goals & Objectives

Our goal in this project is to review the current case studies & symbols used in the English, French, and Aboriginal booklets and to revise them to be culturally appropriate for use with the Inuit. In order to achieve this goal, our group created several smaller objectives:

- Conduct a literature review to establish a baseline for our knowledge in Inuit culture and learning styles.
- Identify location of our target population
- Understand the cultural health care views of the Inuit.
- Understand the delivery of healthcare in Nunavut to create realistic case studies for our target population.
- Research traditional Inuit symbols and find ways to incorporate them into the workbook
- Contact and attend a Hepatitis C support group for Aboriginal and Inuit populations living in the lower mainland.
- Meet with our community leader to review our findings and case studies.

Inuit Holistic Learning Model



Inuit Populations in Canada

Inuit in Canada, Inuit Nunaat and elsewhere, 2006

| Geographic Areas | # of Inuit |
|---|---------------|
| a) Inuit in Canada | 50,480 |
| b) Inuit in Inuit Nunaat (homeland) | 39,475 |
| Inuit in Nunatsiavut | 2,160 |
| Inuit in Nunavik | 9,565 |
| Inuit in Nunavut | 24,635 |
| Inuit/Inuvialuit in Inuvialuit region | 3,115 |
| c) Inuit outside Inuit Nunaat (homeland) | 11,005 |
| Inuit in all urban centres (large and small) | 8,395 |
| Inuit in large urban centres of 100,000+ people | 4,220 |

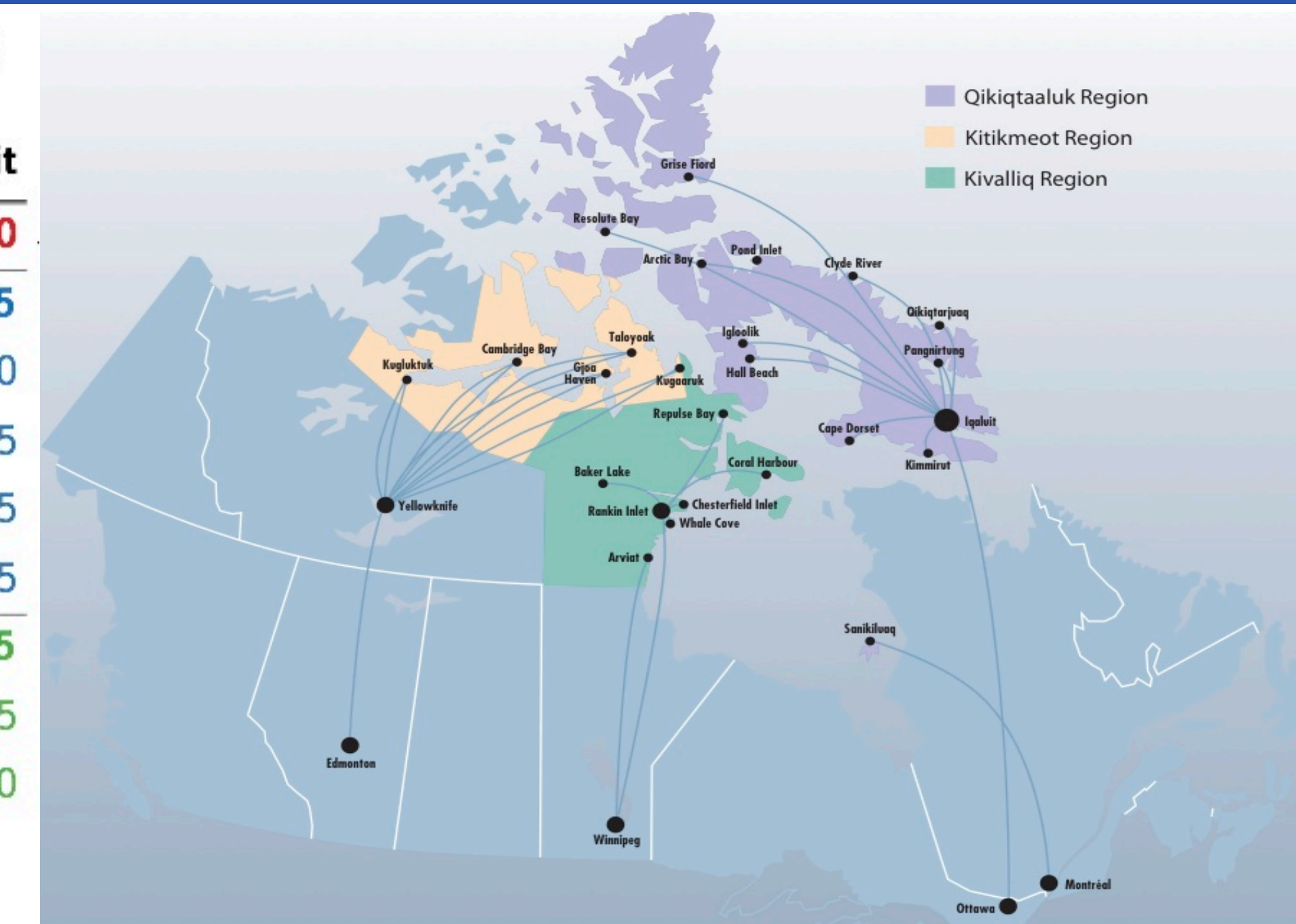


Fig 1. Inuit access to specialized medical services by region

Traditional Inuit Symbols



The Circle Significance

The circle is seen as a symbol of importance and empowerment. The Inuit believe in the interconnectedness of all life, the continuous cycle of life, death and regeneration that links the past, present and future.

Suggested Use

Throughout the workbook, images and text are framed in squares. We suggest that those shapes be changed to circles.

The dissemination of knowledge contained in the workbook could be done through a Circle of Knowledge



Inukshuk (plural Inuksuit) Significance

The Inukshuk is traditionally used to show direction to travellers or allow people to mark their own way

Suggested Use

Learning how to become an effective self-advocate is a journey. The workbook could incorporate Inuksuit as a symbol that helps identify directions that the reader can use to develop their advocacy skills

The Next Step

The BC CDC is working in partnership with Inuit health agencies to adapt the workbook to reflect the needs of the Inuit living in Nunavut. They plan to take our suggestions and modified case studies to a focus group for approval and modification by stakeholders in Inuit communities.

Take home message for nurses working with Inuit populations

- It's important to take the time to form relationships and build trust
- The literacy rates in this population are lower and English is often a 2nd language. Keep this in mind when developing and implementing resources.
 - The Inuit face unique barriers in accessing health care services
 - The importance of bringing someone with them for support
- Inuit wellness takes a holistic approach to care incorporating culture and traditional ways of healing that need to be recognized in the development of resources