

Welcome!

Community Engagement in Indigenous Health Research

Wednesday, May 12, 2021, 12:00 - 1:00 pm
(NST)

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Keep in touch

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Community Engagement in Indigenous Health Research

Drs. Russell Dawe & Zhuxi (Xixi) Gong
with Jack Penashue (video)

May 12th, 2021

Disclosures

- ▶ No conflicts of interest to disclose.
- ▶ This project was funded by a NL SUPPORT Patient-Oriented Research Grant.
- ▶ Indigenous community partner approval given for this presentation.

Land Acknowledgement

We acknowledge that the lands on which Memorial University's campuses are situated are in the traditional territories of diverse Indigenous groups, and we acknowledge with respect the histories and cultures of the Beothuk, Mi'kmaq, Innu and Inuit of this province. We encourage everyone to reflect on the lands where you are located and the Indigenous peoples for whom these lands are traditional territory.

Outline

- ▶ Orientation to the project
- ▶ A word from Jack Penashue - the importance of partnership
- ▶ Narrative overview of our engagement-research process:
 - ▶ Project inception & design
 - ▶ Ethical review processes
 - ▶ Formation of an Indigenous Advisory Committee
 - ▶ Contracts & hiring
 - ▶ Data collection, analysis, & interpretation
 - ▶ Knowledge translation
- ▶ Q&A

Orientation to the Project

The background features abstract, overlapping geometric shapes in various shades of green, ranging from light lime to dark forest green. These shapes are primarily located on the right side of the slide, creating a modern, layered effect. The text 'Orientation to the Project' is centered on the left side of the slide in a clean, sans-serif font.

Patshitinikutau Natukunisha Tshishennaut Uitshuau

**A Place for Elders to Spend their Last Days in Life:
Developing an Innu Approach to Palliative Care**

Investigative Team & Acknowledgements

- ▶ Primary Investigators: Russell Dawe (FOM) & Jack Penashue (SIFN/IN)
- ▶ Co-Investigators: Mary Pia Benuen (SIFN), Anastasia Qupee (SIFN), Andrea Pike (PHRU), Melanie van Soeren (FOM), Nathaniel Pollock (LI), John Knight (PHRU), Carolyn Sturge Sparkes (FOM), Hiliary Martin (FOM), Mercy Winsor (HRU).
- ▶ Thanks also to: Elizabeth Penashue, Francesca Snow, Joseph Mark, Rose Montague, Theresa Andrew, Lorraine Rich, Gabe Woollam, Ashlee Cunsolo, Zhuxi (Xixi) Gong, and to all those who wish to remain anonymous.

FOM: Faculty of Medicine, Memorial University

SIFN: Sheshatshiu Innu First Nation

IN: Innu Nation

PHRU: Primary Healthcare Research Unit, Memorial University

LI: Labrador Institute, Memorial University

HRU: Health Research Unit, Memorial University

Innu Advisory Committee

- ▶ Jack Penashue (co-Primary Investigator)
- ▶ Mary Pia Benuen
- ▶ Anastasia Qupee
- ▶ Lorraine Rich
- ▶ Mary Jane Nui (until time of her death)

Collaborators & Partnerships

- ▶ Innu Nation
- ▶ Sheshatshiu Innu First Nation
- ▶ Faculty of Medicine, Memorial University
- ▶ Labrador Institute, Memorial University
- ▶ Labrador-Grenfell Regional Health Authority
- ▶ Department of Health and Community Services, Government of Newfoundland & Labrador

Project Goals

1. To describe Innu cultural and spiritual knowledge and practices related to death and dying;
2. To describe EOL/palliative medical and community services available to the Innu of Sheshatshiu;
3. To compare rates of home and hospital death for Innu and non-Innu communities in Labrador;
4. To identify aspects of current EOL care delivery that serve the cultural and spiritual needs of the Innu as well as those that fail to meet these needs;
5. To explore ways to integrate current EOL care delivery practices with Innu cultural and spiritual practices to achieve more culturally safe care delivery.

A word from Jack Penashue (co-PI)

Video clip: the importance of partnership.

Narrative Overview of our Process

How we engaged, what barrier and facilitators we faced along the way...

Project Inception & Design

- ▶ **Motivators**
 - ▶ Jack - lived experience & community need
 - ▶ Russell - social accountability & Care of Underserved Populations Program
- ▶ **Meetings**
 - ▶ **Innu Gathering on Gull Island - Sept 2016**
- ▶ **Means**
 - ▶ NL SUPPORT grant opportunity

Ethical Review Processes - OCAP

▶ Ownership

- ▶ Who owns the data? Is there any licensing of data? How is consent managed? Are First Nation(s) attributed as author/contributor?

▶ Control

- ▶ How will First Nations exercise control over data? What happens to data and results upon completion?

▶ Access

- ▶ How can First Nations access their data? Who will be accessing data? What security/privacy policies and procedures are in place?

▶ Possession

- ▶ Will data be held by a First Nation or a First Nation-controlled entity? If not, why?

Ethical Review Processes - OCAP

- ▶ Not just a check list
 - ▶ Individualize to every community
 - ▶ Métis and Inuit
- ▶ Information governance and community privacy
- ▶ “Bad Blood”

Ethical Review Processes - TRC & UN

▶ Truth and Reconciliation Commission - Calls to Action

- ▶ We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends

▶ United Nations Declaration on the Rights of Indigenous Peoples

- ▶ Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

Ethical Review Processes

- ▶ Letter of support: Sheshatshiu Innu First Nations Band Council (at time of grant application)
- ▶ Ethical review & approval:
 - ▶ **Innu Nation** (permission to complete research in Innu territory)
 - ▶ Health Research Ethics Board of Newfoundland and Labrador
 - ▶ Labrador-Grenfell Health Authority

Indigenous Advisory Committee

- ▶ Community Advisory Board:

- ▶ Formation

- ▶ Role of CRB

- ▶ Recruitment of members

- ▶ Operation

- ▶ Decision making protocols

- ▶ Guiding principles

- ▶ Maintenance

- ▶ Evaluation of CAB

- ▶ Sustainability

Indigenous Advisory Committee

- ▶ Community visits: Identifying candidates, exploring local interest in the project, & raising awareness of the work (early iKT)
- ▶ Membership: Elders, leaders (nominations from SIFN & IN), community members
- ▶ Plans, Meetings & Remuneration
- ▶ Relationships/Partnership - connecting early & throughout

Contracts & Hiring

- ▶ Hiring Indigenous Research Personnel:
 - ▶ Identifying candidate(s)
 - ▶ Recruitment
 - ▶ Contract & Human Resources
- ▶ **Indigenous Research Agreement:** research team, Innu leadership, & contracts officer.

Data Collection, Analysis, & Interpretation

▶ *Best laid plans of mice and men...*

Data Collection, Analysis, & Interpretation

- ▶ Planned for interviews
- ▶ Switched community portion to focus group
 - ▶ In Sheshatshiu, at Mary May Healing Centre
 - ▶ With Innu-aimun translation
 - ▶ Innu co-facilitator present

Data Collection, Analysis, & Interpretation

▶ Iterative thematic analysis

Sept 2020:

- ▶ interviews -> preliminary findings to IAC/community -> focus group

Nov 2020:

- ▶ review draft of final analysis with IAC -> town hall

Knowledge Translation

- ▶ Periodic community visits
- ▶ Town hall Nov 2020
- ▶ SHARE Summit & Podcast with NL SUPPORT
- ▶ Poster presentations
- ▶ Online webinars/presentations
- ▶ Community & stakeholder report
- ▶ Peer reviewed journal publications?
- ▶ Social media/other media (not yet taken up)
- ▶ Paintings at Innu Nation & Memorial University

Knowledge Translation



Questions?



References

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http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English_2.pdf
- ▶ UN General Assembly, United Nations Declaration on the Rights of Indigenous Peoples, 29 October 2007, A/RES/61/295, available at:
<https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>