

**Translating Indigenous
Knowledge into Palliative Care
Policy and Practice:
Dissemination Meeting Report**

February 7th, 2013

Six Nations of the Grand River Territory

April 2013

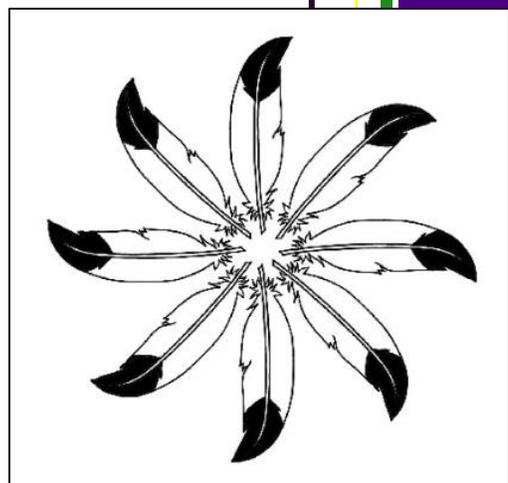


TABLE OF CONTENTS

ACKNOWLEDGEMENTS	2
INTRODUCTION.....	3
OVERVIEW OF THE MEETING DAY	5
SUMMARY OF MEETING RESULTS.....	6
Purpose in Attending the Meeting.....	6
Strategies to Improve Access and Quality of Palliative Care in First Nations Communities.....	7
How Individuals and Organizations Could Assist with the Project	9
Individuals and/or Organizations that Need to be Involved.....	11
Creation of an Alliance to Improve Access and Quality of Palliative Care in First Nations Communities	12
Final Comments	13
NEXT STEPS	14
APPENDIX A	15

ACKNOWLEDGEMENTS

The project team would like to acknowledge and thank each of the participants who contributed to this report, including the representatives of the four partnering First Nations communities, the invited key decision makers from various organizations representing regional, provincial and national health services, and the research team members and staff. This meeting created an awareness of the palliative care needs of First Nations communities and an opportunity for dialogue between stakeholders to identify opportunities to improve quality and access to palliative care in First Nations communities. The outcome of this meeting was the dissemination of new knowledge for all participants: First Nations health care providers, decision-makers, and researchers. Further, we hope to create an alliance with health policy and program decision makers to support community capacity development and improve the health services within First Nations communities. Finally, we would like to acknowledge and thank the Canadian Institutes of Health Research for their financial contribution and support of the research.

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INTRODUCTION

The *Translating Indigenous Knowledge into Palliative Care Policy & Practice* dissemination meeting was funded by the Canadian Institutes of Health Research (CIHR) to share knowledge to date generated from the five-year (2010-2015) Canadian Institutes of Health Research (CIHR) grant “Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development.” The goal of the overall five-year program of research is to develop a model and guidelines for developing palliative care in First Nations communities (see www.eolfn.lakeheadu.ca for more information). This research program is led by Dr. Mary Lou Kelley, Lakehead University, along with seven (7) co-investigators, in partnership with four (4) First Nations communities – Peguis First Nation, Naotkamegwaning First Nation, Fort William First Nation, and Six Nations of the Grand River Territory.

The meeting was hosted by the Six Nations Palliative Care Leadership Team and held in Ohsweken, Ontario on February 7th, 2013 from 9:00 a.m. - 4:30 p.m. at Six Nations Polytechnic. The meeting was attended by seven (7) members of the research team, thirteen (13) members representing the First Nations community partners, and forty-four (44) key decision makers from various organizations representing regional, provincial, and national health services. A list of key decision makers who attended the event is included in Appendix A.

Each of the four First Nations community partners completed a comprehensive palliative care needs assessment in their own community from January 2011 to September 2012. Data included a total of 94 key informant surveys, 21 focus groups with 120 participants, and 41 interviews with 44 participants. The needs assessment included the perspectives of community members, internal and external health care providers and Knowledge Carriers.

Survey questions were designed to gauge the general knowledge and personal opinions related to palliative care of community members. The survey questionnaire contained questions around community members’ awareness, understanding, and experiences in providing palliative care; the practices and beliefs associated with talking about death and dying in the community; the preferred place for end-of-life care; and service and educational needs of community caregivers. Focus groups and individual interviews were conducted using interview guides. Three interview guides were developed,



Members of the Six Nations
Palliative Care Leadership Team
Left to right: Cindy Martin, Lori Monture, Holly
Cowan, Sherry Sandy

one for each of the different participant groups: community members (including internal health care providers), external health care providers, and Knowledge Carriers.

Data analysis included descriptive statistics on the numerical data obtained from the surveys and thematic analysis of the qualitative data from the surveys. Focus groups and interviews were transcribed verbatim from audio recordings. Analytic work included line-by-line analysis of the transcripts to identify themes. For details of the research methodology and findings, please see the project website at www.eolfn.lakeheadu.ca



Gaye Hanson, Researcher and Meeting Facilitator
and Dr. Mary Lou Kelley, Principle Researcher



Participants Engaged in Small Group Dialogue

Throughout this meeting the communities dialogued with decision-makers about the assessment findings and their ideas for developing culturally appropriate administrative, educational, and clinical resources that will improve their palliative care services. This visioning dialogue sought to understand and also take into account the realities of health care decision-making processes.

The objectives of the meeting included:

- 1) Disseminating project knowledge (Presentation on the project, research results and website)
- 2) Creating dialogue between participants to identify opportunities to improve quality and access to palliative care in First Nations communities
- 3) Identifying partnerships to develop and implement culturally appropriate strategies in the communities

OVERVIEW OF THE MEETING DAY

9:00 – 10:00 a.m.	<p>Opening provided by Odyegwani Thomas, Six Nations of the Grand River Territory</p> <p>Welcome Remarks:</p> <ul style="list-style-type: none"> • Ruby Miller, Director of Health Services, Six Nations Health Services • Lori Monture, Chair, Six Nations Palliative Care Leadership Team • Dr. Mary Lou Kelley, Principle Researcher, Lakehead University <p>Overview of Goals for the Day – Gaye Hanson, Researcher and Facilitator</p> <p>Introduction of the Participants</p>
10:00 – 10:15 a.m.	Break
10:15 – 11:00 a.m.	<ul style="list-style-type: none"> • Context of Palliative Care and Health Service Delivery in First Nations Communities presentation – Valerie O’Brien, Researcher • “Improving End-of-life Care in First Nations Video” • Background and purpose of the “Improving End-of-life Care in First Nations Communities” project – Mary Lou Kelley
11:00 – 12:00 p.m.	<p>“Improving End-of-Life Care in First Nations Communities: Findings from Four First Nations Communities” presentation</p> <ul style="list-style-type: none"> – Holly Prince, Researcher – Melody Wawia, Aboriginal Research Assistant – Holly Cowan, Six Nations of the Grand River Territory – Maxine Ranville, Naotkamegwanning First Nation – Jeroline Smith, Peguis First Nation – Karen Bannon and Luanne Maki, Fort William First Nation
12:00 – 1:00 p.m.	Lunch Break
1:00 – 1:45 p.m.	<ul style="list-style-type: none"> • Current Environmental Opportunities for Change – Mary Lou Kelley • Framework for a Multi-Level Approach to Change – Kevin Brazil, Researcher • Panel Presentation: Innovative “Change” Projects <ul style="list-style-type: none"> – Palliative Care Education for Frontline Workers in First Nations Communities in Northwestern Ontario – Holly Prince – CCAC Memorandum of Understanding with Six Nations – Lori Monture, Home and Community Care and Long-term Care – Expert Interdisciplinary Palliative Care Outreach Team, Cheryl Moore, Stedman Community Hospice – Partnership and Mentorship Program in Hospice-Palliative Care between specialized palliative care providers and First Nations health care providers to create a “Shared Care Team”
1:45 – 2:30	Small Group Dialogue and Feedback
2:30 – 2:45 p.m.	Break
2:45 – 4:00 p.m.	Discussion and recommendations on next steps – Creation of an Alliance

SUMMARY OF MEETING RESULTS

Through small group dialogue held within the meeting and voluntary completion of feedback forms left on the table, the following questions were explored by the group:

1. Why did you come to this meeting today?
2. What are some strategies (education, tools/resources, service delivery partnerships, policy initiatives, etc.) you think would help improve access and quality of palliative care in First Nations communities?
 - a) How can you or your organization help?
 - b) Who else needs to be involved?
3. Do you think creating an alliance or network of the people in this room would be helpful?
 - a) Who else needs to be invited?
 - b) How do you see the structure and function of such an alliance working?

Purpose in Attending the Meeting



Participants Engaged in Small Group Dialogue

Through the small group dialogue, participants discussed why they chose to attend the meeting and what their expectations were for increased knowledge and benefits to themselves or their organizations. Participants identified three purposes for attending the meeting. First, and most important, was learning about the project. Specifically, participants were interested in: project activities to date; gaining cultural understanding, identifying innovative practices, and gaps in services. The second purpose was networking – sharing information, collaborating with

participants, and establishing new connections. The third purpose was to identify new knowledge and practices that could be relevant to their workplace. Many participants were in attendance due to their job description or portfolio(s) at their place of employment.

Strategies to Improve Access and Quality of Palliative Care in First Nations Communities

Participants’ shared their perspectives about strategic ways to improve palliative care to First Nations communities. They discussed how they and/or their organization could help and also who else needs to be involved in this process. Four main themes emerged: 1) Service delivery partnerships/policy initiatives; 2) Tools and resources; 3) Education; and 4) Funding. These are elaborated below.

1. Service delivery partnerships/policy initiatives

This theme focused on the need to create formal agreements and memoranda of understanding, along with the development and/or implementation of policies:

Initiatives	Processes	Stakeholders and Goals
Agreements and MOUs between service providers and First Nations communities to improve access and quality of service	Strategy to support establishing an understanding of all the service delivery players, their roles, their mandates, etc. First Nations representation on EOLCN committees/Networks	Pain and Symptom Management Consultant programs First Nations patient navigator Community Care Access Centres Local Health Integrated Network Hospitals Ministry of Health and Long Term Care
Development and/or implement new policies	Identify the specific policy needs and promote involvement of decision makers in creating the answers Ensure all invested at table – not just policy makers or not just stakeholders, both together	Create end-of-life services into essential service as per FNIHB Create accountability agreements for policy and funding Apply Jordan’s Principle as needed FNIHB, First Nations, LHIN’s get together to discover/explore innovations, real working solutions, Home & Community Care program and EOLCN. Improved discharge services

2. Tools and Resources:

- a) Tools and resources that were identified as potential strategies to develop or enhance current care programs in First Nations communities
- Standardized drug kits (through CCAC) and instructions
 - Community palliative care manuals
 - Resources and liaisons for families going through “the system”
 - Traveling hospice
 - Discharge document
 - Information on existing resources/programs, contact information for services currently available in communities
 - Use of technology to improve service(s)
 - Guidelines and planning tools for discharge (template/checklist)
 - Resource for having sensitive dialogues
 - E-Health technology
- b) Tools and resources that were identified as dissemination strategies for key stakeholders in provincial and federal health services and to the public at large:
- Formal tool kit for End-of-Life Care Networks
 - Discharge planning and support systems done in advance
 - Regional, provincial and national webinars semi-annually
 - Information sharing networks and connections (including Lakehead website)
 - Effective dissemination of research project information
 - Disseminate innovative and best practices



Luanne Maki and Karen Bannon,
Fort William First Nation Project Leads



Pauline Thomas, Jeroline Smith and Doris Bear
Peguis First Nation Project Leads

3. Education

Educational strategies suggested included education/training/workshops for families and culturally relevant, culturally safe training for health care providers:

- Education for families, including pain support and “how to” ask the right questions – create comfort in the system and where to find assistance
- Education for health care providers and hospice programs to improve awareness of First Nations communities (e.g. challenges they’re facing, their encounters in dealing with palliative care, awareness of Aboriginal cultural/traditional practices)
- Developing culturally relevant/sensitive palliative care education curriculum

4. Funding

While there were no real strategies identified to address funding issues, it was stated that funding is an important element to ensure projects continue and are sustainable.

How Individuals and Organizations Could Assist with the Project

Three overarching areas of how participants or their organization could assist with the project emerged. These areas included: 1) Involvement, information sharing, and commitment; 2) Advocacy; 3) Program assistance and education.

1. Involvement, Information Sharing and Commitment

The majority of participants felt they could, at this early point in the project, commit their personal or their organizations’ time and resources to this particular endeavour. Creating linkages, continuing dialogue and sharing information were the main ways put forth to offer assistance:

- Moving forward together and continuing the dialogue
- Connection with local linkages as needed per clients’ needs
- Assist in distributing information and being a central contact
- Collaboration of initiatives
- Entering into agreements around care delivery and funding
- Inviting project team to present to LHIN CEO’s in 2012. Push to get conferences at the LHIN’s to bring the players in the region together to begin dialogue
- By highlighting this work, by adding tools on the website, and by sharing with our networks
- Invite First Nations representatives to participate on the regional end-of-life care network committees and working groups. Ensure First Nations input into regional palliative care plan.

2. **Advocacy**

Advocating on behalf of First Nations was seen as a way by participants to assist, at this time, with the project and the continued success(es):

- First Nations communities can help by advocating and stressing the importance of the needs of the client/patient who requires palliative care and support
- Hospice palliative care networks can advocate by relationship building and creating awareness
- LHIN's can be a strong player in moving this forward as they have a mandate to act
- Advocate for end-of-life care and share information
- Advocate for palliative care in First Nations, develop teams
- Advocate for in-team expertise
- Advocate for Aboriginal cultural programs, influencing community capacity to support end-of-life, cancer care, and chronic disease management



Participants Engaged in Small Group Dialogue

3. **Program Assistance and Education:**

Participants felt that they or their organization could offer program assistance and/or education with a specific focus on First Nations culturally safe based care:

- Support curriculum design and evaluation, support research
- The Mississauga Halton LHIN can ensure some training of providers to help create some culturally appropriate services
- Sharing resources through an online site, participation in networks, knowledge exchange with partners
- Create culturally specific materials and training to assist people

- HNHB CCAC should set an example to all other CCAC's to support, mentor, and teach how to relate and be available to all First Nations people
- Mentoring
- Look at existing resources within their area and look at how they can be a part of a provincial network providing supports – cultural competencies, training for regional health facilities
- Continue to develop resources, training, policy and best practice

Individuals and/or Organizations that Need to be Involved

An extensive list of people and/or organizations at all levels – regional, provincial and federal, who were felt should be involved, was developed by the participants in the small group discussions and those that filled out the feedback form:

Within First Nations	Regional	Provincial	Federal/National
Elders and Knowledge Carriers	Local Health Integration Networks (LIHN's)	Provincial policy makers	Federal policy makers
Family	Community Care Access Centres (CCAC's)	Senior Ministry representations (ADM)	FNIHB
Community Members	Dilico Anishinibek Family Care	Ontario Hospice Association	ANADC
Chief and Councils	Regional health authorities	E-Health	
Churches	Hospitals	Ontario Ministry of Aboriginal Affairs	
	Health service providers	PTO's	
	Palliative care providers		
	EOLC Networks		
	Aboriginal Patient Navigators		
	Palliative care outreach teams		

Creation of an Alliance to Improve Access and Quality of Palliative Care in First Nations Communities

On the feedback form, participants were asked if “Would creating an alliance of the people in this room be helpful? Who else needs to be invited? How do you see the structure and function of such an alliance working?” The goal of the alliance or network would be to create a group of allies and advocates to support the development and success of the project until 2016.

Thirty-five (35) feedback forms were returned. Of these, twenty-eight (28) respondents agreed that creating an alliance or network would be helpful. None responded in the negative; however, four (4) said ‘I did not know’, one (1) said ‘maybe’, and one (1) said ‘I think so’. Participants gave an extensive list of who, in their opinion, needs to be a member of the proposed alliance to help improve access and quality of palliative care in First Nations communities. The list ranges from community, regional, provincial and federal levels:

- Elders and Knowledge Carriers
- Caregivers and family members
- Chief and Council and members of local leadership
- Ministry of Health and Long-term Care (MOHLTC)
- Community Care Access Centres (CCAC’s)
- Aboriginal Health Centres
- Palliative Pain and Symptom Management Consultant Programs (PPSMCP)
- Federal and provincial policy makers and representatives from government
- Local Health Integration Network (LHIN)
- End-of-life Care Networks (EOLCN)
- Hospice Palliative Care Ontario (HPCO)
- Quality Hospice Palliative Care QHPCCO
- Cancer Care Ontario, Cancer Care Manitoba and Aboriginal Patient Navigators
- Non-insured Health Benefits
- All levels of care including front line workers, physicians,
- Larger regional hospitals that serve Aboriginal populations
- First Nations political organizations and government agencies

Participants that submitted feedback forms had many great suggestions on how they envision the structure/function of an alliance or network:

- Good communication
- Board of Directors structure
- Concept of what each community wants it to look like. Will it meet its intended purpose?
- Policy development and policies
- Network, website, involve Provincial and Federal policy makers

- Sharing information, best practices and research
- Lead by First Nations leadership
- Informal until there emerges an urgent need for more structure
- Look at this group and even a broader group gathering at least annually for the remainder of this project. Becomes a system wide focus group for the research
- Needs to have strong representation of First Nations, Inuit, Metis
- Needs to have impact results in change – with a regional, provincial and national focus
- Try to align with structures already underway
- The alliance would set the standards based on the findings of the project and advocate for equitable funding in order to support the delivery of care as it needs to be in each community
- Website, sharing information, allowing individuals programs, agencies, gov't to participate.
- Maintaining it through the project for now and then maybe CERAH as a lead
- With the aging needs to increase so does the services supports that we provide including palliative end of life. Gap in services for end of life NIHB
- Yes, list serve the groups have to today and meet at least once a quarter web-based to show your latest research finding and how LHINS, FNHIB, and First Nations and implementing the new information in the/through the declaration and end of life networks etc.
- Take a look at PANACEA E-Health Evaluation and the British Columbia Alliance for Telehealth Policy and Research (BCATPR)
- Network created to share ideas, common issues and solutions. Have resources in shared space to be leveraged by participants come together annually, semi-annually to present on common topics
- Terms of reference, goals, a secretariat, if it's a more journal alliance
- Make sure all parties are heard and I think a good job was done today in regards to this
- Sharing stories from communities with key decision makers/policy people/upper management is very powerful and will stimulate action. Need to keep hearing these stories so that we know where to make improvements!
- Perhaps a "small" yet diverse and representative group. Cross juridical, cross province, cross nations, cross organizations
- What is the goal? I need to move towards something not just wool-gatherings; I am by nature goal-oriented

Final Comments

Some participants offered up some general comments, closing thoughts, on the meeting and project:

- Thank you for inviting our institution to be here. Great day and very important project. Love that you are engaging decision makers so early!
- Advantageous while research still happening
- Maintaining and keeping interest is difficult task

NEXT STEPS

The intended outcome of this meeting was dissemination of new knowledge for all participants: First Nations health care providers, decision-makers and researchers. Materials related to this meeting, including this report and copies of presentations slides will be mounted on the project website in May 2013.

At the end of the meeting, the project team announced that a follow-up on-line survey would be created and emailed to all participants who were invited to the dissemination meeting. The purpose of the survey will be to explore the creation of an alliance with health policy and program decision makers to support community capacity and development and improve the health services within First Nations communities. This alliance could continue over the next three years to support development of program and policy guidelines to improve access to palliative care services for the growing population of First Nations people who need palliative care services and seek to die at home.

APPENDIX A

Name	Organization
Alethea Kewayosh	Cancer Care Ontario
Ariane Tilstra	Mississauga Halton LHIN
Ashley Mt. Pleasant	Student Nurse
Beth Lambie	Erie St. Claire End of Life Care Network
Bill McBain	Heart and Stroke Foundation Ontario
Carol McKenna	HNHB Hospice Palliative Care Network
Cheryl Moore	Stedman Community Hospice
Dr. Denise Marshall	McMaster University
Denise Zuwala	HNHB Community Care Access Centre
Donna Loft	Chiefs of Ontario
Gertie Mai Muise	SW & Erie St. Claire LHIN
Heather Westaway	HNHB Hospice Palliative Care Network
Henry Wilson	Opaskwayak Cree Nation
Hilary Mettam	NW Ontario End of Life Care Network
Janet Bentley	Student Nurse
Janet Noble	HNHB Community Care Access Centre
Jolene Mercer	Assembly of Manitoba Chiefs
Julie Darnay	HNHB LHIN
Kyle Johansen	Central LHIN
Leanne Kitchen Clarke	Canadian Hospice Palliative Care Association
Marg Poling	Palliative Pain & Symptom Management Program
Marlene Sackaney	Algonquins of Pikwakawagan First Nation HCC Program

Maura Purdon	Erie St. Claire End of Life Care Network
Melanie Morningstar	Assembly of First Nations
Melissa Seagull	Canadian Partnership Against Cancer
Michelle MacDonald	Tech Value Net
Dr. Mike Harlos	Canadian Virtual Hospice
Dr. Mone Palacios Mackay	University of Calgary
Peggy Dick	Champlain LHIN
Dr. Richard Scott	University of Calgary
Richelle Miller	West Haldimand General Hospital
Rob Stinchcombe	Northwestern Ontario Community Care Access Centre
RoseMarie Baker	Palliative Pain & Symptom Management Program
Ruby Miller	Six Nations Health Service
Sara Urowitz	Cancer Care Ontario
Sheila Parekh	Aboriginal Health Strategy – MOHLTC
Shelley Corey	Canadian Virtual Hospice
Sommer Aubert	Student Nurse
Susan Warner	Southwest LHIN
Tina Garlow	Student Nurse
Todd Ross	Toronto Central LHIN
Usman Aslam	Cancer Care Ontario
Vanessa Follon	First Nations and Inuit Health Branch, Home and Community Care Program, Ontario Region
Wray Maracle	Six Nations Elected Council of the Grand River Territory