Report on the Assembly of First Nations

SHARING HONOURING PRACTICES IN THE CONTINUUM OF CARE:

First Nations Palliative and End-of-Life Care National Roundtable

May 30 – 31, 2023 • Toronto, Ontario

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Sharing Honouring Practices in the Continuum of Care:
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Day 1: May 30, 2023
- National Updates
- Assessing Strengths
- Identifying Challenges

Day 2: May 31, 2023
- Sharing Innovative Practices

Knowledge Keeper – Rosella Kinoshameg, Wikwemikong First Nation
Facilitator – Holly Prince, Contractor
Notetaker – Melissa McKelvey
AFN Lead – Jonathan Luke Dunn, Senior Policy Analyst, AFN Health Sector

This report was composed and compiled utilizing the extracted text from the session summaries provided by the notetaker.

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Abstract

In May 2023, the Assembly of First Nations (AFN) convened a national roundtable titled "Sharing Honouring Practices in the Continuum of Care: First Nations Palliative and End-of-Life Care." This event took place in Toronto, Ontario, on the traditional territory of the Mississaugas of the Credit First Nations, the Haudenosaunee, and the Wendat peoples. Over the course of a day and a half, the roundtables were facilitated by Holly Prince and brought together AFN staff, a Knowledge Keeper, and numerous First Nations representatives from across the country. The event was structured into four distinct components, each serving a specific purpose:

1) Providing national updates concerning palliative care from the AFN, Health Canada and Indigenous Service Canada's (ISC) First Nations and Inuit Health Branch (FNIHB).
2) Assessing regional strengths related to palliative and end of life care (PEOLC) within First Nations.
3) Identifying regional challenges, addressing the obstacles and difficulties faced in delivering these crucial care services.
4) Sharing innovative practices, allowing participants to exchange valuable insights and learn from successful initiatives taking place in different regions.

Overall, this roundtable served as a platform for knowledge sharing, collaboration, and progress in advancing First Nations PEOLC. It is not to be considered as consultation.

Role of the AFN and the AFN Health Sector

The AFN is a national advocacy organization that works to advance the collective aspirations of First Nations across Canada on matters of national or international nature and concern. The AFN hosts two assemblies a year where mandates and directives for the organization are established through resolutions directed and supported by the First Nations-in-Assembly (elected Chiefs or proxies from member First Nations).

In addition to the direction provided by Chiefs of each member First Nation, the AFN is guided by an Executive Committee consisting of an elected National Chief and Regional Chiefs from each province and territory. Representatives from five national councils (Knowledge Keepers, Youth, Veterans, 2SLGBTQQIA+, and Women) support and guide the decisions of the Executive Committee.

The AFN Health Sector is mandated to protect, maintain, promote, support and advocate for First Nations inherent, Treaty and constitutional rights, wholistic health and well being of First Nations.

The most recent directives to advancing PEOLC services are *AFN Resolution 19/2019*[1] and *AFN Resolution 44/2022*[2].

Objectives

The goal of the national roundtable was to bring together First Nations regional representatives to speak to and participate in discussions about the current PEOLC landscape and determine ways to improve PEOLC services from a community, regional and national level.

Roundtable Structure and Overview

To meet the objectives, the AFN designed a day-and-a-half in-person event, divided into four sessions. The first session focused on national updates regarding PEOLC from the AFN, Health Canada, and ISC. Followed by three sessions facilitated by Holly Prince dedicated to exploring community strengths to supporting existing PEOLC services, challenges in achieving equitable PEOLC, and sharing innovative practices in improving PEOLC. Engaging discussions took place within small groups, with a diligent notetaker recording high-level summaries of the presentations and roundtable discussions.

The national roundtable was opened and closed by Elder Rosella. Her presence brought spiritual grounding through prayer and cultural reflections each day. Drawing upon her nursing background and traditional knowledge, she actively participated in discussions, providing valuable insights. In her closing remarks, Elder Rosella reflected on the key highlights from each session and concluded the event with a final prayer.

1 *AFN Resolution 19/2019, Developing a Seven Generations Continuum of Care for First Nations, by First Nations of Health, Economic and Social Services* – a mandate that calls for developing a Seven Generations Continuum of Care that is wholistic in its approach and can provide a continuum of supports and services to ensure health, social and economic wellbeing for First Nations as they age and as their care needs change.

2 *AFN Resolution 44/2022, Co-Developing Policy Options with Indigenous Services Canada for a Memorandum to Cabinet on the Wholistic Long-term and Continuing Care Framework* – a mandate for AFN to co-develop policy recommendations with ISC on the Wholistic Long-term and Continuing Care Framework, concerning the Assisted Living and First Nations and Inuit Home and Community Care Programs.

Opening Cultural Reflections

The opening prayer was delivered by Elder Rosella Kinoshameg from Wikwemikong First Nation. Setting the tone for the gathering, she began by emphasizing the aspiration of the national roundtable, which was to share honouring practices for PEOLC within the community. Elder Rosella prompted participants to reflect on their personal preparations that brought them to this national event. After some participants shared their personal accounts, Elder Rosella noted the room's signatory name that the national roundtable was held in, entitled the 'atrium', meaning, 'a place to prepare'. She signified the symbolism and correlation between the purpose of this roundtable and our personal life and that when embarking on a journey, there are various things one needs to know and complete before leaving home.

Elder Rosella's reflections turned to preparing for end-of-life. She emphasized the importance of a lifetime of preparation, starting from childhood rather than waiting until the end of life. Elder Rosella encouraged the significance of learning and knowing the traditional teachings and accepting that death is only a transition. As one is born at sunrise and passes on at sunset, with the end of life viewed as 'going home', she advocated for a shift in western terminology, replacing 'life-threatening' or 'life-limiting illnesses' with language that offers comfort rather than fear.

Central to Elder Rosella's message was her expression of the importance of providing peace and comfort to individuals at the end of life; accepting their transition to a different place, and facilitating a good death for individuals at the end of life. She added the importance of savouring the sweetness of life, as neglecting it could lead to illness. Understanding our connection to the Creator, knowing our origins, destination, and the path to return to the Creator were identified as crucial aspects of being ready for life's journey, including the transition to the spirit world.

Session One: National Landscape and Updates

AFN Presentation

The AFN Senior Policy Analyst, Jonathan Luke Dunn, welcomed participants to the national roundtable and proceeded in providing a national update on PEOLC. He emphasized the primary aims of PEOLC, which focus symptom relief and improving the quality of life for individuals with chronic and life-limiting illnesses. End-of-life care supports people in their final stages, striving to meet their goals such as pain management, maintaining dignity, and/or spending time with loved ones. However, First Nations palliative care faces challenges due to the lack of resources and the need for culturally appropriate practices.

Palliative care is relevant at any stage of life. Therefore, PEOLC within a continuum of care, needs to be continuous, dynamic and wholistic in its approach to ensure that an individual's needs are met over their lifetime. An effective continuum of care should involve prevention, intervention, and post-vention strategies, encompassing not only the physical needs but also the emotional, spiritual, and mental components of wellness, while addressing the social determinants of health.

The presentation further discussed AFN's mandates to date and highlighted opportunities for advancing PEOLC through the reform of the First Nations and Inuit Home and Community Care (FNIHCC) Program, which covers palliative care services for First Nations on-reserve.

In 2019, the Federal Budget allocated $8.5 million for Inuit and First Nations-led engagements to identifying priorities for reforming the Assisted Living (AL) and FNIHCC Programs into a wholistic Long-term and Continuing Care Framework. This process produced 32 First Nations regional reports that were submitted to ISC and combined into the National Engagement Summary Report (NESR), which was synthesized by the Ontario Welfare Administrators Association and NORDIK. Based on the NESR and available regional reports, AFN identified seven key reform priorities; culture as foundation; adopting a wholistic approach; restructuring and advancing infrastructure; scalable and sustainable resources; building and supporting health human resources; governance and self-determination; and ensuring equitable access to services across Canada.

Driven by AFN Resolution #19/2019 and AFN Resolution #44/2022, the AFN regularly meets with ISC, reviewing the reform priorities in comparison to the current policies, terms and conditions, and existing funding of the AL and FNIHCC Programs. The goal is to co-develop policy recommendations for transformative change, which will be submitted at the upcoming Special Chiefs Assembly in December 2023.

Health Canada Presentation

Health Canada's Tanya Nancarrow and Katarina Pintar presented on Health Canada's commitment to support improvement of palliative care through an Indigenous Distinctions-based PEOLC Framework. In 2017, parliament passed the *Framework on Palliative Care in Canada Act*, resulting in the production of the Framework on Palliative Care in 2018 and the Action Plan on Palliative Care in 2019. To implement the Action Plan, Budget 2021 allocated Health Canada nearly $30M over six years, which included a small envelope for the development of an Indigenous PEOLC Framework and investments into improving palliative care in Indigenous communities. Health Canada stated that they had met with the AFN Chiefs Committee on Health[3] (CCOH) in 2018 and 2022 to solicit input from the AFN on approaches to a distinctions-based PEOLC framework and a national awareness campaign. The CCOH advised Health Canada to review the existing documents and processes, including First Nations input into the wholistic continuum of care reform process, and develop a framework to be then validated by First Nations. Therefore, Health Canada secured an Indigenous Organization to draft the Indigenous distinctions based PEOLC framework, including a chapter to reflect First Nations' goals and recommendations to improve palliative care.

The framework has Peoples-specific chapters and overall is designed for communities, healthcare organizations, educators and all levels of government affiliates for improving PEOLC. The aim would be to bring forward and identify First Nations, Inuit and Metis recommendations, ensuring Indigenous Peoples could see themselves within the document. The framework would outline shared visions of care (rooted in First Nations knowledge and culture, reflect community strengths, decolonizing the western modality of health), shared understandings (family and community centered and self-determination), and shared pathways that demonstrate core dimensions of Indigenous PEOLC detailing 1) Culture as foundation, 2) Answers in community, 3) Equitable access (jurisdiction and funding), 4) Grief, loss and bereavement, 5) Culturally safety, 6) Capacity building, 7) Infrastructure and resources, 8) Coordinated partnerships, 9) Data, research, evaluation and quality improvement, and 10) Special care considerations.

Health Canada stated they are seeking First Nations validation. Health Canada's projected timelines for the framework validation including Spring 2023 for releasing the first draft of the PEOLC Framework, Summer and Fall of 2023 to develop and validate the framework, and Spring 2024 to finalize the PEOLC

3 The Chiefs Committee on Health (CCOH) is an AFN advisory body comprised of a representative Chiefs from each of the twelve AFN regions across the country and is chaired by the AFN Executive Committee member (Regional Chief) who holds the portfolio for health. The CCOH subsequently reports back and is accountable to First Nations-in-Assembly.

policy framework[4]. Health Canada stressed that the implementation of the framework would work collectively with First Nations and ISC.

Indigenous Services Canada Presentation

ISC's Vanessa Follon and Robin Cano began their presentation by stating that the First Nations and Inuit Home and Community Care (FNIHCC) was not government created but was collaboratively created with First Nations and Inuit partners in the late 1990's As of 2023, the FNHICC has been in operation for 24 years with 386 programs delivered, tailored to community needs with unique and distinct service delivery plans. The program is nursing-led with certified Personal Support Workers (PSW). The program is based on a 40-hour work week with the ability of flexible hours. They highlighted that there were no increases in funding until 2017 [5].

There are nine essential service elements which include structured client assessment; personal care services and home management; data collection and a client records system; care coordination/case management; in-home respite care; access to medical supplies and equipment; home care nursing services; home support services; and established linkages. The supportive elements are home based palliative care; respite care; social services directly related to continuing care issues; rehabilitation and other therapies; home based mental health services; specialized health promotion; adult day programming; support services to maintain independent living; and wellness and fitness.

ISC provided highlights of current FNIHCC initiatives related to palliative care across the regions, Atlantic, Quebec, Ontario and Manitoba that had themes of end-of-life education and training, building palliative care programs, hospice like spaces, and discharge planners. ISC noted that they are working closely with Health Canada in contributing to the development of the Indigenous distinctions-based PEOLC framework and is committed to support implantation efforts of the framework when completed. ISC has presented graphs demonstrating where palliative care and chronic disease management meet. The graphs showed varying diseases (cancer, organ system failure, and fragility/dementia) and the connection between a person's level of autonomy and self-care from onset of diagnosis to end of life. The graphs showed that depending on the disease, there is a variation in trajectory of self-care autonomy however over time there is decline, whether gradual or imminent, requiring a smooth transition from chronic disease management to PEOLC. ISC spoke

4 Since the release of this report, Health Canada's timelines have been updated. Health Canada's projected timelines for the framework validation included; Summer 2023 releasing the first draft of the PEOLC Framework; Fall of 2023 / Winter 2024 to develop and validate the framework; and Summer / Fall 2024 finalizing the PEOLC policy framework.

5 It should be noted that the 2017 budget occurred only after strong advocacy by First Nations who pointed out that the program had not received an increase in years and that the program funding numbers were calculated using population figures from the time of the program's inception.

to the Accessible Canada Act[6] which ensures policy and programs make palliative care accessible, removing and preventing barriers to care.

Question and Comment Period

There were various comments captured:

- A shared concern arose regarding FNICC as being a "catch-all" program incapable of supporting or funding PEOLC let alone chronic disease management, exacerbating the lack of resources for preventative initiatives.
- Recognizing the potential confusion arising from medical jargon and the complex health services, it was emphasized that FNIHCC must empower First Nations with self-management models.
- Reassurances were provided regarding the alignment of efforts between ISC and Health Canada (FNIHB was historically under Health Canada and is now managed by ISC[7]). They expressed that they are employing a whole of government approach, collaborate closely to enhance PEOLC services and funding for First Nations communities.
- In response to a question addressing two decades of identified service gaps and NIHB policy constraints, the plan for correction involves reforming the FNIHCC program by co-developing policy recommendations with AFN and ISC to improve Long-term and Continuing Care and PEOLC.
- The call for improved policy advocacy was acknowledged, emphasizing that policy reform should be complemented by responsive measures, particularly needs-based funding that accurately reflects community requirements.
- Regarding the authorship and review process of Health Canada's PEOLC Framework, it was disclosed that an Indigenous contractor is spearheading the initial drafts. Furthermore, the framework is undergoing two rounds of peer reviews involving First Nations, Inuit and Métis partners to ensure cultural relevance and accuracy.

6 The Accessible Canada Act, Bill C-81, came into force in 2019 to ensure a barrier-free Canada. The purpose involves identifying, removing and preventing barriers in federal jurisdiction. The design and delivery of programs and services such as PEOLC is included in this Act.

7 The transfer of the First Nations and Inuit Health Branch from Health Canada to Indigenous Services Canada occurred in 2017.

Session Two: Assessing Community Capacity

Holly Prince facilitated the discussion centered around the evaluation of community capacity, assessing the strengths within the communities that can be mobilized in providing care. The following aspects were highlighted: First, the recognition of First Nations' cultural values, beliefs, and teachings as foundational elements contribute significantly to community well-being. Second, the significance of relationships and connections, emphasizing the importance and strong demonstration of kinship in communities. Third, a spotlight on the existing strengths and capacities within the community itself, which can be leveraged to support comprehensive care initiatives.

A notable concern discussed was the prevalent issue of delayed diagnoses among First Nations individuals, necessitating the imperative to facilitate earlier diagnosis. Racism emerged as a substantial barrier, often causing individuals to be marginalized with the healthcare system and avoiding or delaying diagnosis. To address these challenges, there was a call for increased support within the community, enabling community members to receive care within their culturally safe and familiar surroundings.

The Indigenous wellness framework was introduced, highlighting the interconnectedness of various dimensions of wellness. Physical wellness was identified as a source of purpose, spiritual wellness as a wellspring of hope, emotional wellness as a creator of belonging, and mental wellness as a cultivator of meaning. Within the context of PEOLC viewed through an Indigenous lens, several critical elements were emphasized. These included the involvement of Elders, National Native Alcohol and Drug Abuse Program (NNADAP), crisis intervention programs, grief counselors, Community Health Representatives (CHR) or Community Health Educators (CHE), as well as community and family members. Traditional wellness programs and healers, alongside spiritual guides and clergy, were considered integral components.

A fundamental perspective emphasized was that First Nations should not be viewed through a deficit-based lens. Instead, a focus should be placed on identifying the strengths and positive aspects inherent within each community. The presentation concluded with a compelling question: "What are the good things present within your community?" This inquiry underscored the importance of recognizing and capitalizing on the existing positives within First Nations.

Assessment of Services Roundtable Discussion

During the roundtable discussion, participants engaged in a reflective exploration of the care options available to those who are sick or nearing the end of life within their respective communities. The diversity of resources aimed at addressing wholistic care needs emerged as a central theme. Participants provided insights into patient and family access to care, caregiving entities, and care settings.

- In Manitoba, jurisdictional ambiguity was noted, contributing to challenges in care provision. Nursing care, particularly for palliative cases, was highlighted as accessible within homes. Many nurses often expressed gratitude to be a part of family care and embraced cultural elements such as drumming, music, and donning of traditional attire. While homecare staff emerged as strong advocates, pain management remained an area of concern, indicating a need for further progress.
- Shifting focus to Alberta, a combination of traditional and non-traditional approaches to PEOLC was acknowledged. The experience of a sole individual currently receiving palliative care in a hospital setting underscored the reality of home caregivers facing limitations.
- In Saskatchewan, opportunities to work with AIDS clients were hindered by the doctor's hesitance, compounded by inadequate pain management training. Addressing these challenges would involve breaking down barriers and elevating the role of nurse practitioners.
- Ontario noted that they have NIHB Navigators, however cited they have difficulty of ensuring early diagnosis in northern and remote communities. Persistent issues of medical transportation posed ongoing difficulties.
- A perspective from the Northwest Territory highlighted the struggle with PEOLC services, as services are delivered by the Government of Northwest Territory (GNWT). Funding is channeled through GWNT and little is directed towards First Nations communities. There is a lack of physicians in communities. Hospitals allow traditional customs and ceremonies to be honoured. However, the option of dying at home is not occurring.

The importance of family and community support was consistently emphasized, with participants recognizing the significant role these networks play in care provisions. When discussing policy and program development, participants called for a strengthened focus on nursing and home support care, particularly for those lacking family support. The overarching goal was to facilitate more accessible, culturally sensitive, and home-based care options, emphasizing the profound impact of community involvement in the care journey.

Community Strengths Roundtable Discussion

The roundtable conversation centered on the strengths inherent in end-of-life care within diverse communities. Participants offered insightful reflections and anecdotes, shedding light on the distinctive attributes that contribute wholistic care provision.

- Nova Scotia emphasized the strong bonds of community, where mutual care and shared humour play integral roles in coping with challenging circumstances. They highlighted the inclusivity of families during the end-of-life process, with children actively participating in wakes and gatherings and shared instances of hospitals accommodating traditional practices, such as the provision of 'liquid smudge' and respectful family gatherings. Acknowledge the profound impact of COVID-19 on end-of-life experiences, particularly the emotional burden of individuals passing away alone.
- Alberta illustrated the significance of familial support and humor in facilitating care at home for individuals nearing the end of life. They highlighted the role of Elders' Committee in bridging traditional and modern protocols, imparting teachings about death and cultural practices. They discussed efforts to honour individuals' preferences to pass away at home, facilitated by ambulance services and tailored healthcare units to allow traditional practices and they underlined the importance of engaging Elders in discussions, including complex topics like Medical Assistance in Dying (MAID) and the need for culturally sensitive practices.
- Prince Edward Island and Manitoba participants shared the value of nursing support and collaborative leadership within healthcare teams to deliver effective end-of-life care in a home setting. They emphasized the role of mental health services and adaptive leadership in addressing emerging care needs and mentioned the presence of navigators and the consideration of community language preferences to enhance communications and understanding. They also noted the co-existence of provincial services alongside on-reserve programs.
- Northwest Territories and Saskatchewan shared personal experiences reflecting a strong sense of community duty and the significance of preserving cultural practices in end-of-life care. They underlined the importance of language and traditional rituals in creating meaningful experiences for individuals and families and advocated for community-focused education, particularly for healthcare staff, to ensure the continuity of cultural practices and traditions. They also spoke of efforts to reclaim and celebrate cultural heritage, learn from Elders, and integrate their wisdom into modern care practices.

- Ontario acknowledged the resilience and commitment displayed by communities in supporting families during and after the end of life. They discussed collaborative efforts between long-term staff and Tribal Councils, showcasing a commitment to skill sharing and mutual support and highlighted the challenges of working within limited resources while striving to provide comprehensive care. They also recognized the importance of amplifying community voices and perspectives in shaping effective care strategies.

Throughout the discussions, a common thread of family support, cultural preservation, and community collaboration emerged as pivotal strengths in offering compassionate and culturally sensitive end-of-life care. The participants shared insights and experiences underscored the significance of learning from one another and adapting successful approaches to enhance care provisions.

Session Three: Identifying Challenges to Overcome

Regional participants engaged in a profound dialogue to identify critical obstacles within their communities' ability to provide optimal care for individuals facing illness or nearing the end of life. This discussion encompassed three essential dimensions: challenges within the community's care provision, hurdles in health service delivery, and systemic challenges within the broader healthcare framework.

- Manitoba and PEI participants recognized that lack of funding is a substantial challenge, with the need to address racism and the social determinants of health equally significant. The constraints of NIHB and jurisdictional ambiguity were highlighted, impacting care delivery. Additional challenges encompassed the lack of supports for caregivers, absence of modern technology, limitations in ambulatory care and transportation, and insufficient personal care homes.
- Northwest Territories noted that the absence of 24/7 services and inadequate availability of cultural practices as pressing issues. Challenges associated with cultural respect, medical transportation, and NIHB policies further complicate care access. A comprehensive 'wish list' was presented, spanning social worker support, education on sexually transmitted diseases, enhanced data management, funding for traditional health practices, recognition of nurse practitioners, and addressing funding discrepancies based on outdated population statistics.

- Ontario outlined the persistence of racism, gaps in data concerning community needs and program effectives, and jurisdictional gaps posing significant challenges. The scarcity of health human resources, affecting staff retention and skill development within the community, was a central concern. Access barriers, even within urban settings, and challenges associated with NIHB were identified.
- British Colombia highlighted that the transportation of opioids required extraordinary efforts and requires systemic change.
- Nova Scotia emphasized inadequate funding for staff and the imperative for cultural training. Concerns over unsafe medical spaces, marked by racism and stereotypes, were raised, with a specific inquiry regarding space for Indigenous clients within newly established facilities. Social determinants of health, lack of community awareness about the need for palliative care (not solely end-of-life care), and scarcity of physicians were significant hurdles. The reactive nature of NIHB and the lack of proactive character were identified as challenges.
- Alberta voiced issues with IV therapy, the social determinants of health (detailing water and housing), and the reluctance to acknowledge the natural progression towards death and dying posed difficulties. Safeguarding cultural practices, the allocation of NIHB resources (including supplementary supplies like Ensure for palliative patients) were discussed.
- Quebec included an emphasis on the pivotal role of training, which stands as a prominent challenge. The intricate interplay of language poses as a prominent challenge. They highlighted the need for extending additional support to informal caregivers, predominantly family members or relatives, acknowledging their vital contribution to the care dynamic. Challenges pertaining to death certificates and the transportation of remains have also come to the forefront, particularly when distinguishing between ambulance and funeral home services.

The multifaceted conversation illuminated the need for collaborative action to address funding disparities, combat racism, enhance cultural awareness, bridge jurisdictional gaps, bolster healthcare human resources, streamline NIHB policies, and establish robust support systems for caregivers.

Session Four: Sharing Innovative Practices

During the roundtable session, participants engaged in dynamic discourse aimed at sharing lessons learned and groundbreaking approaches to provide culturally safe PEOLC. Facilitated by Holly Prince, the session revolved around the crucial themes exploring – 1. Improving access to PEOLC recognizing innovative strategies, 2. Regional and community-based models showcasing approaches that prioritize cultural sensitivity and effectiveness, and 3. Community visions for change that foster a community-led vision for transformative changes in PEOLC.

- New Brunswick established a steering committee of 10 Elders, creating a preventative wellness lodge focused on land-based learning for youth. Cultural integration was emphasized, and the site served as a traditional meeting space.
- British Columbia implemented virtual doctors and primary care centers, adapting the death doula curriculum to align with Indigenous culture.
- Ontario highlighted the role of navigators in interacting with hospital staff and service providers, playing a crucial role in a circle of care planning. Efforts to raise awareness of available services beyond NIHB were noted, along with the establishment of a connected palliative care network and streamline access to programs. Additional representatives of Ontario highlighted diverse languages and challenges in fly-in communities. There is an aim to revive languages and traditional ways of knowing and exploring partnerships and focusing on housing and economic development. A seniors complex with daycare is being built, but some features are pending. Funding constraints persist and has prompted a wellness plan to improve health.
- Nova Scotia shared insights about ambulance palliative care teams and emphasized the importance of mental wellness teams. The retention and recruitment of NIHB navigators, hospital navigators and Mi'kmaq speakers to enhance communication were outlined.
- Alberta engaged in online training for paramedics and nursing, while collaboration with Alberta Health Services (AHS), nurse practitioners and social workers was highlighted. A notable initiative in Edmonton called 'George's House' led by a doctor focused on providing space for urban Indigenous individuals at the end of life. Alberta introduced innovative virtual cancer care and home therapy programs at Maskwacis First Nation. Before the COVID-19, a significant step was taken through a Memorandum of Understanding (MOU) with AHS to address cancer care within the community. With a combined population of 18,000 across four nations, there was a concerning rise in cancer rates. Community health and mental health initiatives collaborated,

engaging in productive talking circles that invited cancer patients to voice their needs. The consensus highlighted the need for accessible chemotherapy options within the community, minimizing the need to travel to Edmonton or Camrose. As part of this effort, plans were made to extend the community healthcare facility to incorporate a chemotherapy unit, aligning with the goal of enhancing local healthcare services. Additionally, the concept of virtual care played a role in facilitating improved accessibility and support.

- Quebec shared insights about training nurses to maintain skills and a community-based system to ensure current skills among nursing and social services.
- Saskatchewan's Peter Ballantyne Cree Nation introduced Elder coordinators, responsible for transportation, escorts, translation, and other support services. They described collaborations with funeral homes to preserve cultural practices, including cedar baths, dressing, and traditional burial practices. Efforts were noted in traditional child health, homecare, and cultural practices around bereavement and mental health therapy. Engagements with hospitals for emotional support during stillbirths and miscarriages, access to traditional health in communities, and cultural training for nurses and home health aides were discussed.
- Northwest Territories highlighted the presence of wellness programs across their 36 communities and one reserve, focused on nurturing the well-being of youth, Elders, and caregivers. Elder involvement was emphasized in these initiatives, contributing to the revival of coming-of-age traditions. Language and cultural resources are provided for nurses and caregivers across five regions, each with distinct practices. Navigators play a crucial role in advocating for Elders during end-of-life stages, ensuring families have essential information. While palliative care is provided though the GNWT, attention is directed towards resolving potential issues related to NIHB to ensure seamless community support.
- PEI, despite a small population and only two reserves, focus their efforts on prevention. A diabetic nurse visits biweekly, and endeavors are underway to secure on-reserve dialysis services and methadone dispensing. The introduction of innovative patient navigators has proven invaluable, aiding appointments, advocating, and translating. Collaborative partnerships with the province permit hospital involvement and discharge planning. The region is also addressing the challenges of an aging population, emphasizing long-term PEOLC.

Holly Prince shifted the conversation into her closing presentation on 'Indigenous-led Approaches to Program Development,' and several key points were discussed:

One aspect highlighted was the use of dictionaries for medical terminology to ensure accurate communication of information. The process of developing palliative care programs was outlined, involving considerations such as infrastructure, collaboration to break down silos, empowerment through leadership and elder involvement, and a vision for change. Local leadership engagement and catalysts like education or community experiences were emphasized as important drivers of program growth.

Partnerships and advocacy were identified as crucial components in program development, focusing on advocacy, clinical care, and education. A workbook aimed at guiding the development of Palliative Care Programs in First Nations was introduced.

The presentation also introduced training opportunities for frontline workers through a course entitled 'Palliative Care for Frontline Workers in Indigenous Communities.' This two-day in-person course has trained over a thousand individuals since 2019, providing a safe space to discuss sensitive topics like death and dying, and offering therapeutic benefits for healthcare providers. Webinars were also highlighted, covering a range of topics including Indigenous ways of grieving, handling difficult conversations, managing expected deaths at home, and pain management.

Various resources and training initiatives were mentioned, such as 'Preparing for the Journey,' 'Community Caregiver' curriculum (online and free), 'Delivering Culturally Safer LEAP Education for Indigenous Communities,' and 'Living My Culture.ca,' which provides advance care planning guidelines. Additionally, the 'Indigenous Culturally Safety training: advanced illness, palliative care and grief' program offered by Canadian Virtual Hospice was introduced as valuable resources.

As the roundtable drew to a close, regional participants were acknowledged for their invaluable contributions and sharing their significant success stories. Holly Prince validated their efforts in recounting these stories, emphasizing that the journey towards meaningful change begins at the community level. She highlighted the crucial principle of not employing a top-down approach but rather fostering collaborative growth from within each community. This underscored the importance of learning from each other's accomplishments, using them as sources of inspiration and guidance, as well as leveraging shared wisdom to formulate grassroots solutions.

Closing Cultural Reflections

In the concluding remarks, Elder Rosella Kinoshameg provided insights that resonated within the context of healthcare and community well-being. She emphasized the importance of going beyond the call of duty in healthcare work, noting the admirable efforts of palliative care ambulances and mental health outreach teams. She underlined the significance of being a steadfast support for those in need, emphasizing the invaluable role that community members have in providing assistance during times of illness and approaching end-of-life stages.

Furthermore, Elder Kinoshameg stressed the preservation of cultural practices and traditions in healthcare. Her call to keep cultural ceremonies and practices alive, even during challenging circumstances, highlights the essential connection between cultural heritage and well-being. Elder Kinoshameg shared the importance of knowing and respecting First Nations languages, as they hold deep cultural and spiritual significance, particularly in end-of-life situations. She candidly addressed challenges faced by communities, including funding limitations and racism. Drawing from the Truth and Reconciliation Commission's Calls to Action and the UN Declaration, she advocated for cultural training and the recognition of Indigenous rights as vital steps towards achieving equitable and respectful healthcare. Elder Rosella touched upon the need for greater health human resources, particularly nursing staff, and encouraged community members to pursue careers in health sciences.

In closing, Elder Kinoshameg encouraged perseverance in the face of challenges and the importance of returning to traditional practices and medicines to ensure revitalization for healthier and vibrant communities.

Appendix

Compendium of Opportunities

The listed opportunities were selected from the dynamic discourse, then paraphrased and assembled into overarching themes to serve as a reference. These opportunities do not function as a complete or absolute list of recommendations concerning PEOLC, however, serves as an overall reflection of highlighted points emphasized by the national roundtable participants. Please note the entities holding the responsibility for each listed actionable item are not assigned as most recommendations could be understood to be within the realm of the federal / provincial / territorial governments, regional health authorities, service providers, tribal councils, and/or at the community-level of jurisdiction.

1. **Culturally Sensitivity and Community Involvement**
   - Recognize and integrate First Nations' cultural values, beliefs, and teachings.
   - Accommodate traditional practices within healthcare settings.
   - Emphasize language preferences and cultural rituals for meaningful experiences.
   - Involve Elders, Knowledge Keepers, traditional healers, and community members in care initiatives.

2. **Equitable Access and Care Provisions**
   - Address delayed diagnoses and racism barriers.
   - Enhance nursing care, pain management, and home support.
   - Improve medical transport options, particularly in remote areas.
   - Strengthen focus on nursing and home support care.

3. **Collaboration and Partnership**
   - Enhance collaboration between traditional and non-traditional approaches
   - Collaborate with hospitals, tribal councils, and provincial services
   - Establish patient navigators, ambulance palliative care teams, and mental wellness teams.
   - Form partnerships with healthcare providers, advocate for comprehensive care and the inclusion of culturally safe care.

4. **Training and Education**
   - Provide training for healthcare providers on culturally sensitive care.
   - Offer various training programs for frontline workers and caregivers.
   - Educate nurses and healthcare on cultural practices and language
   - Conduct training sessions on Traditional ways of grieving and end-of-life care.

5. **Funding and Resource Allocation**
   - Address funding disparities and lack of resources.
   - Advocate for increased support within the community.
   - Improve funding for traditional health practices and community wellness programs.
   - Allocate resources for specialized equipment and palliative care units.

6. **Community Strengths and Resilience**
   - Focus on community bonds, mutual care, and shared humour.
   - Acknowledge and leverage existing strengths within each community.
   - Recognize the significance of family and community support in care provisions.
   - Emphasize community involvement and grassroots solutions for change.

7. **Systemic Change and Policy Reform.**
   - Address jurisdictional ambiguity and healthcare system barriers.
   - Combat racism within healthcare spaces.
   - Develop programs and initiatives guided by First Nations-led approaches.

8. **Streamlining Non-Insured Health Benefits**
   - Streamline NIHB policies to ensure timely access to care.
   - Address issues of medical transport, transportation, and escorts.
   - Advocate for proactive and culturally sensitive care within the NIHB framework.
   - Reduce barriers in accessing medical services, treatments, and equipment through NIHB.

9. Palliative Care as an Essential Service Element

- Designate palliative care as a core element of FNIHCC.
- Ensure culturally appropriate and well-funded palliative care services.
- Provide specialized training for healthcare providers.
- Regularly assess and refine the palliative care policy.

10. Establish a National First Nations and Inuit Home and Community Care Knowledge Exchanging Table

- Form a committee comprising of diverse representation to facilitate updates, innovative solutions, and lessons to inform effective FNIHCC policies and practices.
- Hold federal government accountable for FNIHCC policy implementation, with progress updates and assessments.
- Prioritize equity, cultural sensitivity, and community-based solutions in FNIHCC services.

Participation List

Abegweit First Nations
Akiatcho Region
Assembly of First Nations (AFN)
Atlantic Policy Congress of First Nations Chiefs Secretariat
Chiefs of Ontario (COO)
Dene Nation
Federation of Sovereign Indigenous Nations (FSIN)
File Hills Qu'appelle Tribal Council
First Nations Health and Social Secretariat of Manitoba (FNHSSM)
First Nations Health Authority (FNHA)
First Nations of Quebec and Labrador Health and Social Services Commission
Health Canada
Indigenous Services Canada (ISC)
Kee Tas Kee Now Tribal Council
Lakehead University
Lennox Island First Nations
Little Grand Rapids First Nations
Maskwacis Health Services
Mawiw Council
Nishnawbe Aski Nation (NAN)
Sturgeon Lake Health Centre
Wolastoqey Tribal Council

SHARING HONOURING PRACTICES IN THE CONTINUUM OF CARE:

First Nations Palliative and End-of-Life Care National Roundtable

May 30 – 31, 2023 • Toronto

AGENDA

DAY ONE:		
TIME (EDT)	**ACTIVITY**	**FACILITATOR**
9:00 – 10:00	**Breakfast**	
10:00 – 10:30	**Opening Prayer and Cultural Reflection**	Elder Rosella Kinoshameg
10:30 – 11:00	**Opening Remarks:** • Identify the need for care for our seniors, Elders, and those living with disabilities, chronic diseases, and mental illnesses.	Jonathan Luke Dunn – AFN Health Senior Policy Analyst
11:00 – 12:00	**Health Canada Presentation** • Report on the draft Indigenous distinctions-based Policy Framework	Venetia Lawless – Manager, Policy Development, End of Life Care Unit / Health Care Programs & Policy Directorate. Health Canada Tanya Nancarrow – Senior Policy Advisor, End of Life Care Unit / Health Care Programs & Policy Directorate. Health Canada Vanessa Follon – Senior Nurse Consultant & National Manager, Home, Community and Preventative Care Division FNIHB, ISC
12:00 – 1:00	**Lunch**	
1:00 – 2:45	**Discussion Issue 1: Assessing Community Capacity** **This session assesses the strengths and capacities within communities that can be mobilized in providing care.** • First Nation's cultural values, beliefs, and teachings • Relationships and connections • Community strengths and capacities	Presentation and facilitated discussion by Holly Prince – Project Manager, Centre for Education and Research on Aging & Health, Lakehead University
2:45 – 3:00	**Coffee and Comforts**	
3:00 – 4:30	**Discussion Issue 2: Challenges to Overcome** **This session identifies gaps in service delivery and challenges within the health system that inhibits access to the best care for community members.** • Challenges within community in the provision of care • Health service delivery challenges • Systems challenges	Presentation and facilitated discussion by Holly Prince
4:30 – 5:00	**Closing of Day One Remarks**	Elder Rosella Kinoshameg

AGENDA

DAY TWO:		
TIME (EDT)	**ACTIVITY**	**FACILITATOR**
9:00 – 10:00	**Breakfast**	
10:00 – 10:15	**Reflections**	Elder Rosella Kinoshameg
10:15 – 11:45	**Discussion Issue 3 – Innovative Practices** This session outlines learned lessons and innovative approaches to provide culturally safe palliative care and seeks to identify an action plan for moving the conversation forward. • Improving access to PEOLC • Regional and community-based models • Community vision for change	Presentation and facilitated discussion by Holly Prince
11:45 – 12:00	**Closing Remarks and Prayer**	Jonathan Luke Dunn Elder Rosella Kinoshameg
12:00 – 1:00	**Lunch**	