

North West **LHIN**
RLISS du Nord-Ouest



Regional Palliative Care Plan

SUPPORT. QUALITY. COORDINATION.

Fall 2014

Value Statement

All of my care providers will work together with me and my family to support our quality of life throughout this journey and respond to our needs in a coordinated way.



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Executive Summary

Background

The experience of death and dying is unique to each individual and is a reality faced by everyone at some point in their lives. Access to high quality palliative care can have a profound impact on the quality of life of both the individual who is dying and their loved ones. In the North West LHIN, the aging population and higher prevalence of advanced chronic disease puts an increased demand on palliative care services. In December 2011 the Ministry of Health & Long-Term Care, Local Health Integration Networks (LHINs), and the Quality Hospice Palliative Care Coalition of Ontario committed to recognizing palliative care as a priority for system transformation with the release of the document “Advancing High Quality, High Value Hospice Palliative Care in Ontario: A Declaration of Partnership & Commitment to Action”. The following plan outlines the North West LHIN’s approach to strengthening the system of palliative care across the region and achieving the vision described in the provincial Declaration of Partnership.

Goal

To develop a comprehensive plan to mobilize, strengthen, and reorient the health care system to improve access to safe, comprehensive, and high quality palliative care for all residents of Northwestern Ontario.

Alignment

All recommendations are aligned with the provincial Declaration of Partnership, Ontario’s Action Plan for Health Care, Ontario’s Seniors Strategy, and the North West LHIN’s Integrated Health Services Plan 2013-2016 and Health Services Blueprint. Utilizing the model of service delivery recommended in the Blueprint, the plan describes how palliative care services will be organized and delivered at the local, district, and regional levels.

Methodology

The palliative care plan was created through the analysis and synthesis of both qualitative and quantitative information. Community engagement was conducted with key stakeholders including frontline providers and informal caregivers. Relevant evidence based models of care were identified through a literature review and scan of key documents from other jurisdictions.

Findings

The following key strengths and gaps were identified within the current system of palliative care in the North West LHIN:

Strengths in the North West LHIN	Gaps in the North West LHIN
<ul style="list-style-type: none"> ▪ Health Service Providers (HSPs) demonstrate a willingness to work together and informal collaboration is a key tenet of providing care in the North West LHIN. ▪ Previous work has established a strong foundational base for creating a regional approach to palliative care. ▪ Quality educational opportunities are available. ▪ Palliative care experts are willing to provide consultation and support to primary level providers. ▪ There are many existing programs and services that can be leveraged to support individuals and caregivers in the community. ▪ Many HSPs recognize palliative care as a core function and would like to develop more formalized programming to support their staff and clients. ▪ Robust models for developing palliative care in First Nations communities & Long Term Care Homes (LTCHs) have been designed in Northwestern Ontario. ▪ Providers from all disciplines and care settings express a desire to enhance their capacity to deliver palliative care through participation in ongoing education and skills development. ▪ Providers are comfortable using innovative technologies to facilitate communication, education, and increased access to care. ▪ Partners are willing to work with the North West LHIN to identify mechanisms to enhance accountabilities around palliative care. 	<ul style="list-style-type: none"> ▪ There has been no regional approach to palliative care planning and delivery in the North West LHIN, making it difficult to coordinate care across settings and communities. ▪ There is no formal mechanism for 24/7 access to palliative care expertise. ▪ There are inconsistencies in the availability of palliative care programs and services at the LHH and IDN levels and timely access to care is a challenge. ▪ Individuals who may benefit from a palliative approach to care are not being identified early and consistently. ▪ There is limited communication and coordination between First Nations community providers and other health care services. ▪ Caregivers do not feel sufficiently informed and supported to fully participate in the care of their loved ones. ▪ There is limited access to ongoing clinical education, experiential learning, and mentorship for providers at all levels of care. ▪ There is little ongoing monitoring, reporting, and evaluation of palliative care programs and activities at the system level. ▪ The EOL Care Network has not had the capacity, accountability to the LHIN, or recognized authority to make sustainable changes to the palliative care system in Northwestern Ontario. ▪ There remains a stigma around accessing palliative and end-of-life care and a reluctance amongst the general population to discuss issues related to death and dying.

Recommendations

The following recommendations will support the development of a comprehensive, coordinated system of palliative care in the North West LHIN. A Regional Palliative Care Program will be created to provide the leadership and oversight for the implementation of this plan.

1. Establish a standardized approach to care across settings and providers.
2. Develop a shared care model for palliative and end-of-life care whereby primary level providers deliver the majority of care with back-up support from secondary and tertiary level experts.
3. Provide 24/7 access to tertiary level expertise for providers across the North West LHIN.
4. Palliative care programming will be available in every health care setting.
5. Explore opportunities to improve access to a full continuum of care across the North West LHIN.
6. Ensure that adequate community supports are available across the North West LHIN to allow individuals to experience a good quality of life and death at home.
7. Collaborate with First Nations communities and organizations to improve access to culturally appropriate palliative care services and support for their members.
8. Provide quality, timely palliative and end-of-life care to individuals with advanced or progressive chronic diseases.
9. Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision.
10. Explore options for the creation of hospice-like spaces in key care settings where people die.
11. Ensure that palliative care education is available and accessible for all providers.
12. Support the use of innovative technologies to provide access to 1) consultation & support, and 2) education & training.
13. Measure, monitor, and evaluate overall system performance.
14. Increase public awareness and dialogue on palliative care.

1.0 Background

In 2005 the Ministry of Health and Long-Term Care (MOHLTC) announced the End-of-Life Care Strategy. Individuals and organizations partnered to form 14 regional networks aligned with the Local Health Integration Network (LHIN) boundaries in support of the provincial strategy. In the North West LHIN, the Northwestern Ontario End-Of-Life (NWO EOL) Care Network was established to provide leadership and structure to the ongoing development, implementation, maintenance and evaluation of a comprehensive, integrated and coordinated system of palliative and end-of-life care throughout the region.

In 2011 key stakeholders, including the MOHLTC, all 14 LHINs, and the members of the Quality Hospice Palliative Care Coalition of Ontario, came together to achieve common consensus on a vision for palliative care in Ontario.

The resulting document, “Advancing High Quality, High Value Hospice Palliative Care in Ontario: A Declaration of Partnership & Commitment to Action” (known as the Provincial Declaration) identifies the steps to be taken to provide equitable access to safe, comprehensive and high quality palliative care and support for individuals and their families across the province.

With the release of the Provincial Declaration, all 14 LHINs committed to recognize palliative care as a priority for system transformation and to use the Provincial Declaration as a basis for broader consultation. Each LHIN also committed to develop a regional implementation plan with a common three year end point and common deliverables.

In order to create an implementation plan for Northwestern Ontario, the North West LHIN engaged the NWO EOL Care Network and its host agency, St. Joseph’s Care Group, to develop a comprehensive regional palliative care plan.

Palliative Care Value Statement

*All of my care providers will work together with me and my family
to support our quality of life throughout this journey
and respond to our needs in a coordinated way.*

(Created by participants at a value stream mapping session, March 2014)

Goal

The overall goal of this plan is to mobilize, strengthen, and reorient the health care system to improve access to safe, comprehensive, and high quality palliative care for all residents of Northwestern Ontario. The plan provides a comprehensive analysis of the current and future state needs for palliative and end-of-life care in the North West LHIN and outlines a clear implementation plan for the next three years.

Alignment with Regional and Provincial Priorities

Alignment with MOHLTC Priorities:

The North West LHIN regional palliative care plan advances the following provincial priorities from Ontario's Action Plan for Health Care:

- The right care, at the right time, in the right place
- High quality care
- Care as close to home as possible
- Low cost - high impact initiatives
- Evidence-based solutions and continuous quality improvement
- Models that build system capacity
- Stewardship of system resources
- Enhanced Chronic Disease Management

Many of the recommendations also align with Ontario's Seniors Strategy. Ontario's Seniors Strategy promotes broadening the range of palliative care services available in all regions, including within the home, hospice, and institutional care settings. Enhancement of home and community care services is also well supported.

Alignment with North West LHIN Priorities:

The proposed model and recommendations for palliative care address the following priority areas in the North West LHIN Integrated Health Services Plan 2013-2016:

- Building an Integrated Health Care System
- Improving Access to Care
- Enhancing Chronic Disease Prevention & Management

Through implementation of the proposed model and recommendations, the North West LHIN will achieve:

- Improved health outcomes resulting in healthier people;
- Access to health care that people need, as close to home as possible;
- Continuous quality improvement;
- A system-wide culture of accountability.

Health Links will be leveraged to advance system re-design and integrate a palliative approach in all care settings using a collaborative, interdisciplinary team approach.

The Service Delivery Model proposed for palliative care aligns with the North West LHIN Health Services Blueprint with implementation at the Local Health Hub (LHH), Integrated District Network (IDN), and Regional Program levels.

More information on how this plan aligns with both provincial and North West LHIN priorities can be found in Appendix A.

Methodology

The palliative care plan was created through the analysis and synthesis of qualitative and quantitative information including:

- Community engagement across the North West LHIN
- Existing reports of the North West LHIN and NWO EOL Care Network
- The Provincial Declaration
- Provincial initiatives led by provincial Hospice Palliative Care Steering Committee
- A literature review focused on rural and remote communities
- Quantitative data from multiple sources

The initial phase of community engagement took place in the fall of 2013 and included a number of community visits, key informant interviews, and a survey of NWO EOL Care Network members (see Appendix B). The second phase of community engagement took place in the winter of 2014 and included a Value Stream Mapping session with frontline providers and caregivers and input from the NWO EOL Care Network's System Integration Working Group and Education & Research Committee. The goal of this phase was to validate the findings from the first round of community engagement and elicit feedback on the emerging themes.

In addition to community engagement, several key documents from other jurisdictions were reviewed. These included models and plans from other regions both in Ontario and other parts of Canada; work completed by the Provincial End-of-Life Care Network and other provincial organizations such as Cancer Care Ontario; the North West LHIN Health Services Blueprint and Integrated Health Services Plan 2013-2016; and previous work completed by the NWO EOL Care Network and its partners.

A literature review was conducted on 'models for palliative care' and 'palliative care in rural and remote areas'. Relevant evidence based models of care such as the integrated model of care and the shared care approach were identified along with a conceptual model for developing rural palliative care using a community capacity building approach (Kelley et al., 2011). Components of these models of care will be incorporated into the regional care model for the North West LHIN. Elements of the literature review will serve as evidence throughout this plan. The complete literature review is available as a supporting document.

An analysis of available quantitative data was also undertaken.

Assumptions

It is acknowledged that there is significant work being done at the provincial level concurrent to the development of this plan. The following assumptions have informed the development of this plan and its recommendations:

- At the time this report was written (September 2014), no new funding from the province (MOHLTC) was available to support the implementation of this plan.
- Performance measures and supporting indicators are under development by the provincial Data & Performance Working Group. The overarching goal is to increase the number of individuals receiving palliative care outside of acute care.
- The provincial Residential Hospice Working Group will be making recommendations on the role of residential hospices in the overall continuum of care. These recommendations may precipitate a change in the MOHLTC's policy on funding for residential hospices.
- The Auditor General of Ontario has conducted an extensive review of palliative care services and will be releasing a report in December 2014 which may include further recommendations for consideration.
- The quantitative data available was limited and inconsistent across sources due to variable coding practices. Inferences have been made as required.

There are several other underlying assumptions that have been informed by community engagement and reinforced by the NWO EOL Care Network Steering Committee:

- Most individuals prefer to die at home. If this is not feasible they prefer to remain at home for as long as possible.
- Most individuals in Northwestern Ontario prefer to stay in their own community hospital versus travelling to Thunder Bay to receive specialized, tertiary care at the end-of-life stage.
- The NWO EOL Care Network with its current structure has not had the capacity, accountability to the LHIN, or recognized authority to make sustainable changes to the palliative care system in Northwestern Ontario.



2.0 Context: Understanding Palliative Care and Why It is Important

Definitions & Terminology

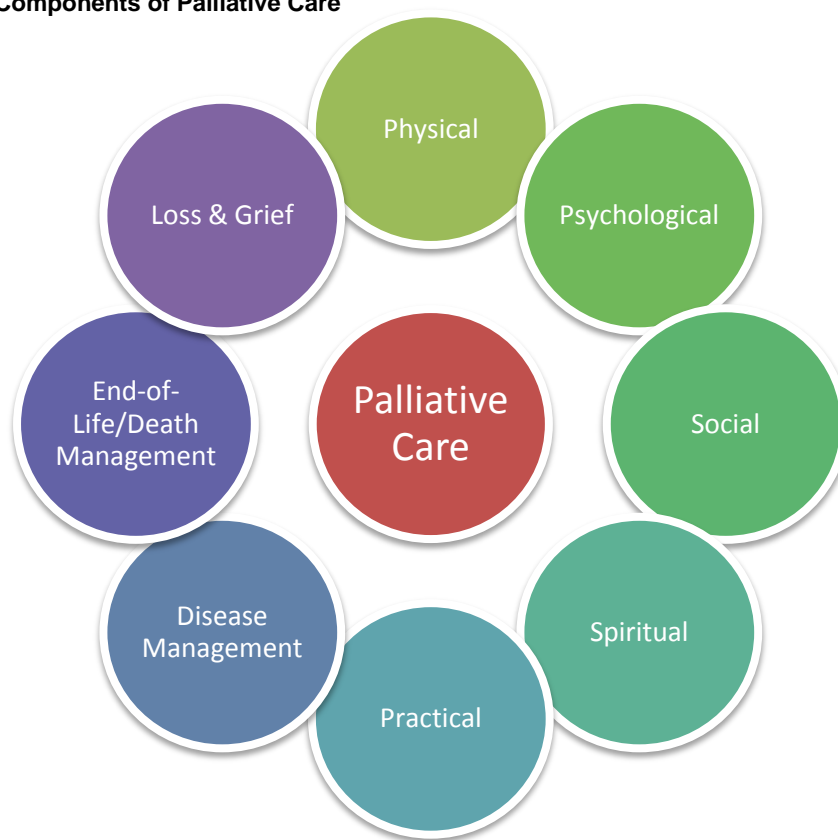
In Ontario, the definition used for hospice palliative care has been adapted from the Canadian Hospice Palliative Care Association's (CHPCA) Model to Guide Hospice Palliative Care (2002).

Hospice Palliative Care, or simply “palliative care”, is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It is an approach to care rather than a diagnosis. It is used to support not only the individual with the illness or disease but their family and other loved ones as well. The terms hospice palliative care (HPC) and palliative care are used interchangeably. Hospice palliative care is not to be confused with residential hospice, which is a particular type of care setting that offers palliative care.

End-of-Life Care is a term used to define the care provided in the final stages of life. While end-of-life care is part of palliative care, it is important to note that a palliative approach to care can and should be introduced prior to the final stage of life.

Palliative care is not limited to addressing physical symptoms or issues but aims to relieve all types of suffering while improving the overall quality of living and dying. The palliative approach to care encompasses all the areas depicted in the diagram below.

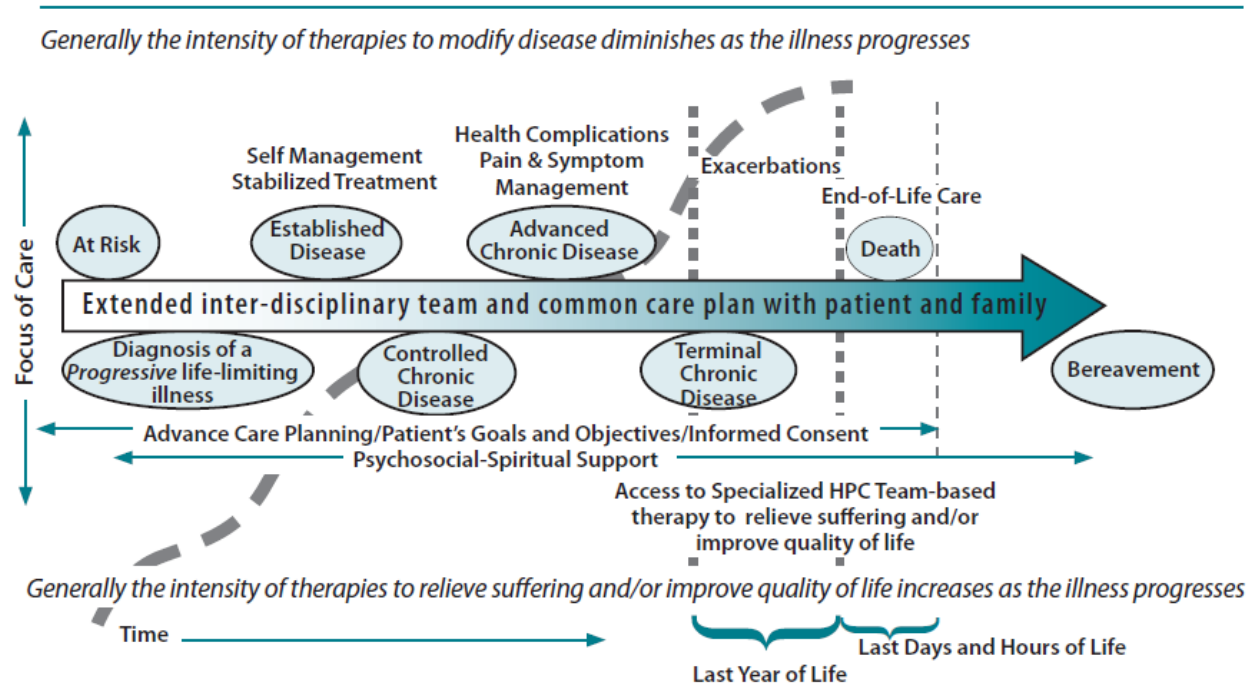
Figure 1: Components of Palliative Care



Source: Adapted from CPHA's Model to Guide Hospice Palliative Care (2002)

The Provincial Declaration has endorsed a model for palliative care, as seen below, that highlights the importance of early identification of individuals and families who could benefit from a palliative approach to care and the continuous provision of care from diagnosis through to the bereavement period following death. Components of this model will be incorporated into the regional model and implementation plan for the North West LHIN.

Figure 2: Child & Adult Hospice Palliative Care – Chronic Disease Continuum Model



Modified (2011, 2013) from the Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care*, 2002
By the Care Pathing Across the Continuum of CDM Working Group, MOHLTC, Ontario

Benefits of a Palliative Care Approach

The benefits of employing a palliative approach to care are numerous and well-documented. A review of the literature reveals that palliative care services can significantly reduce health care costs associated with individuals who are dying (CHPCA, 2012). Palliative care has also been shown to improve the experience of the individual and their family. It is often associated with better symptom control, improved patient and caregiver satisfaction, and greater likelihood of death in the location of choice (CHPCA, 2012).

Delivery of Palliative Care

The majority of palliative care is provided by an individual's primary care provider and informal caregivers with support from secondary and tertiary level experts as necessary. These experts have specific education and training in palliative care and are able to provide support and consultation to primary care providers in helping to manage complex issues. While many individuals who receive palliative care will only require care from their primary care providers, there are some situations where additional expertise or tertiary level care is required.

3.0 Current State Analysis

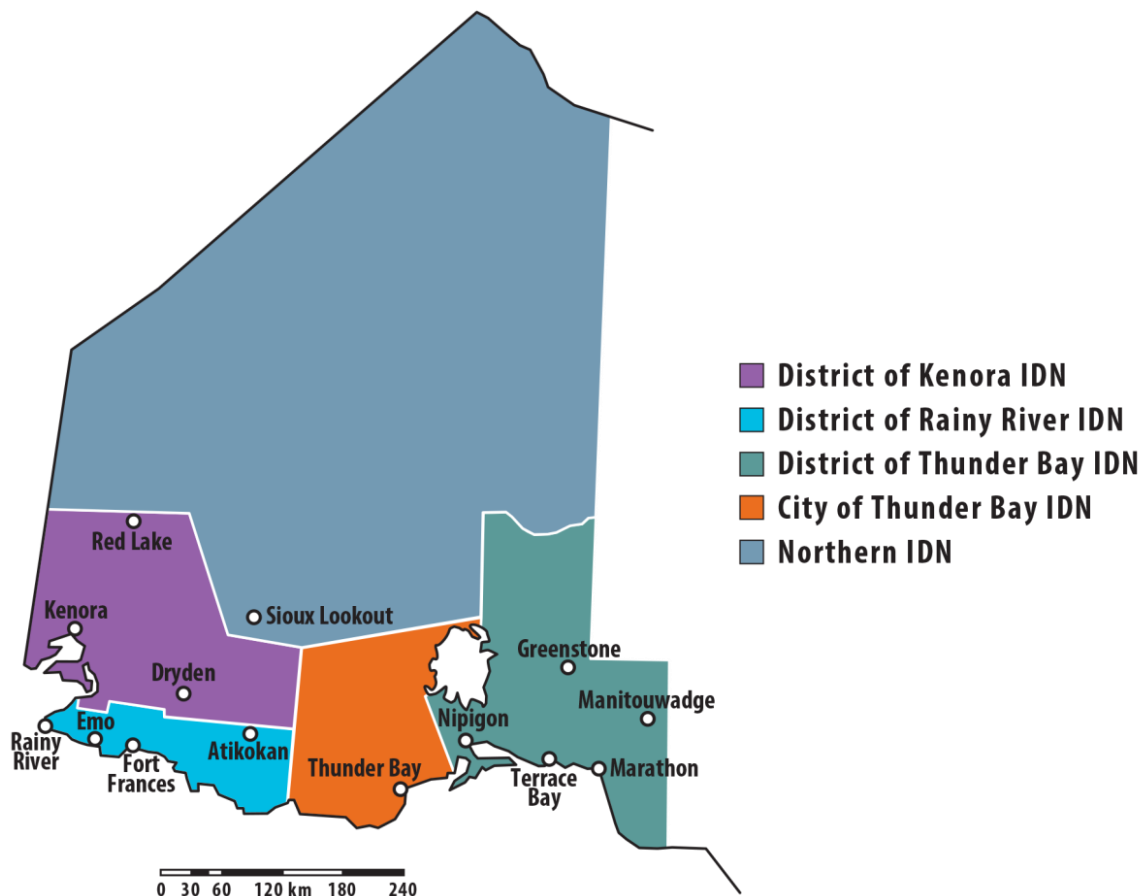
Demographics & Geography

The North West LHIN region has the smallest population of all Ontario LHINs, with approximately 231,000 residents (North West LHIN Population Health Profile, 2013). It also serves the largest geographic area of all Ontario LHINs, covering approximately 47% of the province's land mass. The North West LHIN region has the largest proportion of Aboriginal people of all Ontario LHINs, with approximately 20% of the North West LHIN's population being of Aboriginal descent (North West LHIN Population Health Profile, 2013).

In comparison to the rest of the province, the North West LHIN is projected to have a higher growth in the proportion of seniors (North West LHIN Population Health Profile, 2013). Over the next 20 years, in the North West LHIN, the proportion of those aged 65 and over is projected to increase from the current 15-16% to 27-28% (North West LHIN Population Health Profile, 2013). Provincially the proportion is expected to increase from the current 14-15% to 22-23% (North West LHIN Population Health Profile, 2013). As the population ages, the demand for high quality palliative and end-of-life care will increase.

To guide the planning and delivery of health care services while acknowledging the unique needs across the region, the North West LHIN region has been divided into five Integrated District Networks (IDNs), as shown in the figure below.

Figure 3: North West LHIN Integrated District Networks Map



Many of the IDNs are experiencing an overall decline in total population and an increase in the number of people aged 65 and over. The result is an increasing demand for palliative care amongst the older population with fewer informal caregivers from younger generations to provide the care required, creating a need for stronger community supports.

The following table illustrates these differences in population size, age, language, and Aboriginal identity and illustrates the need to consider the unique characteristics of each IDN when planning for palliative care.

Table 1: 2011 Census Population Characteristics by IDN

IDN	Total Pop. ¹	% Age 65+ ¹	% Aboriginal Ident. ²	% Franco-phone ¹
Northern IDN	21,815	5.5*	81.3*	0.5*
District of Kenora IDN	43,130	15.5	25.5	2.9
District of Rainy River IDN	20,370	17.3	22.3	1.5
City of Thunder Bay IDN	127,715	17.1	9.7	2.8
District of Thunder Bay IDN	18,090	14.0	34.1	13.0
North West LHIN*	231,120	15.8	21.5*	3.3*

Sources: 1. Statistics Canada, 2011 Census. 2. Statistics Canada, 2011 National Household Survey.

* 13 FN communities were not enumerated at the time of the 2011 Census due to forest fires. A follow-up survey was conducted and information is now available; values for Northern IDN and North West LHIN reflect this new information.

In the Northern IDN, for example, there is a smaller proportion of seniors and a large Aboriginal population spread out across a number of small, remote communities. Specific cultural and geographical needs must be taken into consideration while planning for palliative care in the Northern IDN. Alternatively, the City of Thunder Bay IDN has a higher number of seniors living in an urban setting, within close proximity to a range of health care services. In order to meet the needs of the entire population of the North West LHIN, different approaches to enhance the delivery of palliative care in each IDN must be considered, leveraging the existing strengths of each IDN.

Health Status

The residents of the North West LHIN region report poorer health practices than the population of the province as a whole. Poor health practices are known to be related to an increased risk of chronic disease, mortality, and disability, resulting in increased demand for palliative care (North West LHIN Population Health Profile, 2013). Compared to the rest of the province, the North West LHIN has a higher proportion of people who:

- smoke daily
- are heavy drinkers, and
- are overweight or obese

The North West LHIN also has a lower proportion of people who:

- rate their health as excellent or good
- have a regular medical doctor, and
- have had contact with a medical doctor in the past 12 months

(North West LHIN Population Health Profile, 2013)

The population of the North West LHIN exhibits a higher prevalence of many chronic conditions and greater rates of hospitalization compared to the provincial average. The population of the North West LHIN also has a higher incidence rate of prostate, colon, rectal, and lung cancers compared to the rest of the province as shown in Appendix C (North West LHIN Population Health Profile, 2013).

Chronic conditions place a high burden on the health care system. Early intervention and using a palliative approach to care will benefit individuals living with advanced chronic disease and result in better outcomes for the system as a whole (CHPCA, 2012). Higher rates of hospital use for chronic conditions could be due to a lack of alternative community-based services. There is a need to leverage existing primary care and community-based programs to provide enhanced support to those living with complex conditions.

Death & Dying

There are currently approximately 2,000 deaths per year in the North West LHIN region. With the projected growth in the population aged 65 and over, the demand for palliative and end-of-life care will increase as the number of people dying in the North West LHIN region increases. The following table forecasts the expected number of deaths based on population growth and aging. Overall deaths in the North West LHIN region are projected to increase by 27% between 2007 and 2020. In-hospital deaths are forecast to increase by 48% between 2007 and 2020. By 2020, approximately 500 more people will be dying annually than in 2007 (Preyra Solutions Group, 2012).

Table 2: Actual and Projected Number of Deaths in the North West LHIN

IDN	2007 (Actual)	2014 (Projected)	2020 (Projected)
City of Thunder Bay	1134	1289	1457
District of Thunder Bay	168	191	212
Kenora	322	360	414
Northern	88	97	110
Rainy River	202	217	234
North West LHIN	1914	2174	2428

Source: Preyra Solutions Group - North West Mortality Forecast by IDN

While some deaths are sudden and unexpected, the majority of deaths in the North West LHIN region occur as a result of progressive illness or chronic disease. Diseases of the circulatory system, respiratory system, and nervous system are amongst the leading causes of death in the North West LHIN (Vital Statistics, 2013). Having a palliative care approach in every care setting would benefit all dying individuals, and the earlier the palliative approach to care is introduced, the better the outcomes for both the individual, their family and the system as a whole.

As identified during the community engagement process, the location of death is very important. People prefer to die at home or as close to their home community as possible. The table below illustrates that in 2011/12, 67.7% of deaths in the North West LHIN took place in a hospital setting (including acute care, complex continuing care, and Emergency Department), while 18.5% took place in long-term care homes, and 14% took place in private homes.

Table 3: Percent of deaths by location, Ontario, FY2011/12

LHIN of patient residence	Acute Care (including psychiatric facilities)	Complex Continuing Care	Emergency Department	Long Term Care	Rehabilitation facilities	Home with/without support
(14) NORTH WEST	43.8%	16.0%	7.9%	18.5%	0.0%	13.9%
ONTARIO	45.8%	7.7%	5.8%	17.7%	0.2%	22.8%

Data source: Discharge Abstract Database (DAD), Chronic Care Reporting System (CCRS), National Ambulatory Care Reporting System (NACRS), National Rehabilitation System (NRS), Ontario Mental Health Reporting System (OMHRS), Registered Persons Database (RPDB), and claims history.

Compared to the provincial average, the North West LHIN reported more deaths in long-term care and fewer deaths in private homes. In 2011/12, the North West LHIN had the lowest proportion of deaths at home out of all 14 LHINs (MOHLTC, 2013). In a public opinion survey conducted in 2013, 76% of Ontarians expressed a preference to die at home with only 13% indicating hospital as their preferred location to die (CHPCA, 2013). These numbers suggest a great disconnect between the wishes of individuals and families and the actual location of death. In addition, the estimated cost of providing palliative care in the home is approximately \$4,700 per individual compared to \$19,900 per individual in hospital (OACCAC et al, 2010). Therefore, the need to provide palliative care in the right care setting is two-fold: to ensure client-centered care and to improve system efficiency.

Palliative Care Providers & Care Settings

In the North West LHIN, care for dying individuals is provided in many settings, including hospital, long-term care, and community. There is great variability in the quality and consistency of palliative care provided across organizations and communities, as there are currently no region-wide standards for palliative and end-of-life care.

Two thirds of all deaths occur in a hospital setting across the North West LHIN, yet many hospitals have not formally recognized palliative and end-of-life care as a core service. This has led to a lack of a consistent approach to the development of palliative care programming in hospital settings. As a result, staff education in palliative care, access to palliative care

expertise, the self-designation of palliative care rooms and beds, and policies around advance directives and advance care planning varies across the sector.

Long-term care is another important setting where dying individuals are cared for. Similar to hospitals, there is great variability in the formal palliative care programming that is offered by long-term care homes (LTCHs) in the region. However, many LTCHs have identified palliative care as an area in which they would like to make improvements, and the Quality Palliative Care in Long-Term Care (QPC-LTC) research project at Lakehead University has demonstrated success in engaging LTCHs in positive change. The QPC-LTC model and toolkit provide a guide for other LTCHs to develop comprehensive palliative care programming within their organization.

A summary of the palliative care programming currently provided by hospitals and long-term care homes in the North West LHIN can be found in Appendix D and E.

Many individuals are cared for at home for some time prior to their deaths. Appendix F summarizes the services that are currently available to support individuals and their families and caregivers in the community at the LHH level. While there are a number of supports available, many of these services are not connected to primary care, nor are they recognized for their potential role in providing a palliative approach to care to individuals and families in their homes. Lack of coordination and communication between services also creates a barrier to providing seamless care to the individual and family. The differences in the availability of services across LHHs indicates a need for palliative care planning at the local level to ensure the implementation of recommendations is tailored to each community's strengths while addressing the gaps that exist.

There are also a number of programs and services that provide palliative care expertise in the North West LHIN. These programs and services offer support to other settings and providers through a combination of consultation, education, and direct care. Current palliative care programs in the North West LHIN include:

- The Hospice Palliative Care Unit (HPCU) and Telemedicine Nursing program at St. Joseph's Hospital;
- The End of Life Program & Palliative Care Nurse Practitioners (NPs) at the CCAC;
- The Palliative Pain & Symptom Management Consultant Program hosted by the CCAC;
- Hospice volunteer programs through Hospice Northwest and the Kenora Rainy River District Palliative Care Volunteer Program;
- Supportive Care at Regional Cancer Care Northwest; and
- Interdisciplinary Palliative Care Education through the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University.

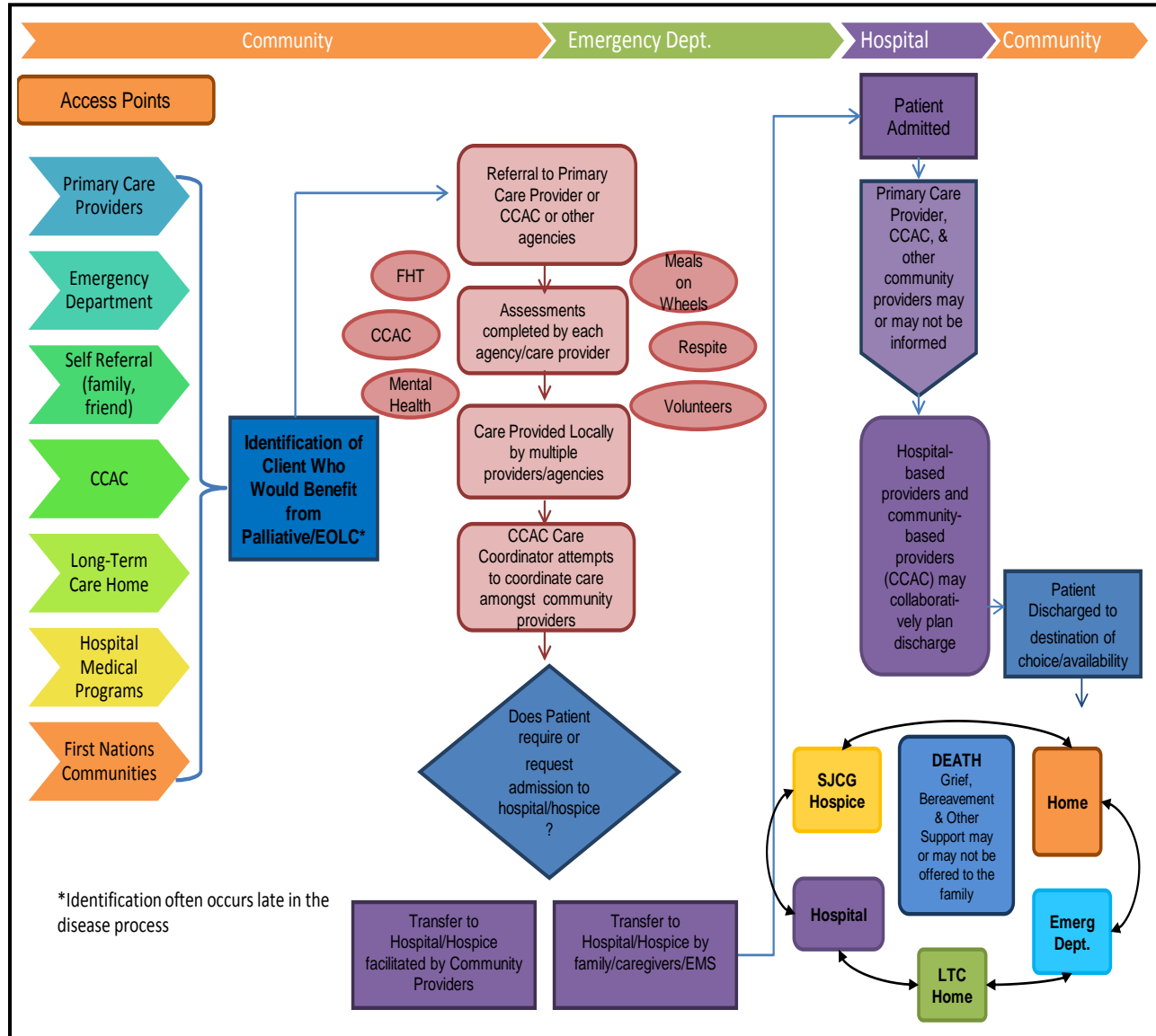
Palliative care providers in the North West LHIN have a strong history of collaboration and partnership. However, these programs operate independently - each with its own mandate, criteria, and resources. As a result it is difficult to integrate palliative care services at the system level to create "one stop" access to palliative care expertise and support.

A detailed description of these palliative care programs and services is provided in Appendix G.

Current Model of Care

The current journey of an individual living with a progressive illness or chronic disease is depicted in the diagram below. This journey map was created by key informants working within the system and was validated through the community engagement process. It reflects the common milestones that individuals and families experience during the provision of care in the last days, weeks, or months of life, while recognizing that each individual journey is different and many factors may influence the type of care received.

Figure 4: Current State Patient Journey Map – Palliative/End-of-Life Care



An individual may enter the system through any number of access points, depending on where they live and who they receive care from. Upon diagnosis of a progressive, life-limiting illness, the health care provider may or may not have a conversation with the individual about the benefits of a palliative approach to care. In most cases, the concept of palliative care is not introduced to the

“My dad was assessed to be palliative about a month before he died even though he had been suffering from the same chronic conditions for several years. I think that the palliative designation should have been explained to us earlier.” ~ A Caregiver

client or family until later in their journey as they near the end of life. According to a survey conducted on behalf of the CHPCA, 87% of Canadians have not done advance care planning, yet 73% would like more information about it from their physicians so that they can begin to have these important conversations with loved ones (CHPCA, 2013). Often it is a crisis situation and admission to hospital that triggers a care provider to discuss palliative and end-of-life care with the client and/or their family.

Client and family engagement and evidence based research reveal that this type of discussion should be introduced earlier in the client’s journey to experience the benefits of a palliative care approach.

Once a care provider has identified a client or family in need of palliative or end-of-life care, they are typically referred to the CCAC for home care services and/or to several different community programs or services, such as Meals on Wheels, all at the same time. Often the client receives care concurrently from a primary care provider and a specialist depending upon their diagnosis.

*“It all felt uncoordinated and was very upsetting... recounting it even now makes me so sad that it was such a tedious and confusing process.”
~ A Caregiver*

A separate assessment may be completed by each organization providing services. There is currently no common record of information that can be shared amongst these organizations. Families report that lack of clear communication between multiple service providers often makes care disjointed. There is an opportunity to improve coordination between the community and hospital sectors when an individual requires acute care.

The importance of ongoing communication amongst all providers was also identified. In the current state this is lacking. However, it was evident from community engagement that care providers in small communities know each other well, resulting in close relationships and the development of informal support networks. Many care providers go above and beyond to meet the needs of the individual and family.

“The community pulls together when someone is in need.” ~ A Provider

Long term care may be an option for those with a longer life expectancy, although it is not always immediately available. Though system partners work together to try to find an appropriate location for care, in many cases individuals will cycle between settings as their condition progresses, until they are no longer able to return home. Lack of available home support was identified as an issue in several communities. There is a perception that more people could experience a quality death in the community if additional professional services were available to support individuals and their caregivers in the home. There is currently no standalone residential hospice in the North West LHIN, although some hospitals and LTCHs have created hospice-like spaces in their facilities.

When primary care providers require support or consultation on a complex case, they will often contact a palliative care expert or service with whom they have a previous relationship. Currently, there is no one clear access point for palliative care expertise, nor is it consistently available after hours. A 24/7 “virtual” team was suggested on numerous occasions to address this gap.

In many remote communities, there are limited community resources. As their health deteriorates many individuals are forced to seek care elsewhere, travelling long distances from their family and friends.

The need for bereavement support was also identified in multiple community engagement sessions. While supports are often available, the bereaved may be unaware of how to access such programs, or the type of programming offered may not meet their needs.

As depicted in the journey map, care is provided by multiple levels of expertise and at many different care settings. Delivery of palliative care varies across the different care providers and settings as there is no standardized approach to providing palliative care in the North West LHIN.

System Strengths

Despite the challenges in the North West LHIN, there are strengths to build upon to enhance the delivery of palliative care. Many services and providers exceed their formal roles and responsibilities to provide the best possible care. Quality research has been completed in the North West LHIN region to develop models for palliative care for First Nations communities, LTCHs, and rural and remote areas.

The following section describes key strengths that were identified through the community engagement process, measured against the components of an integrated palliative care system identified in the Provincial Declaration.

Table 4: System Strengths

Components of an Integrated System of Palliative Care*	Strengths/Levers for Change in the North West LHIN
Integration/Linkages/Education “Sectors and services are linked by common practice, processes, structures, and education.”	<ul style="list-style-type: none"> Providers demonstrate a willingness to work together and informal collaboration is a key tenet of providing care in the North West LHIN. Providers have indicated a desire to work across sectors and settings as members of an interdisciplinary care team. Previous work by community palliative care committees and the NWO EOL Care Network has established a strong foundational base for creating a regional approach. The EOLFN research project at Lakehead University is developing resources to encourage collaboration between First Nations providers and other health care partners. Quality educational opportunities are available through CERAH, NOSM, Lakehead University, and Confederation College.

<p>Care Settings and Services</p> <p><i>“A full continuum of care settings and services is in place as per population based needs.”</i></p>	<ul style="list-style-type: none"> ▪ Palliative care expertise is available through SJCG, TBRHSC, CCAC, CERAH, and hospice volunteer programs. ▪ Palliative care experts are willing to provide consultation and support to primary level providers. ▪ There are many existing programs and services that can be leveraged to support individuals and caregivers in the community. ▪ There are also many non-traditional programs that support clients & families by providing supplemental care such as Meals on Wheels, home maintenance and volunteer support groups.
<p>Programs within Care Settings and Services</p> <p><i>“In each care setting where individuals die, a palliative care program is developed.”</i></p>	<ul style="list-style-type: none"> ▪ Many HSPs have now recognized palliative care as a core function and would like to develop more formalized programming to support their staff and clients. ▪ Robust models for developing palliative care in rural, First Nations communities, and LTCHs have been designed and validated in Northwestern Ontario (Kelley et al., 2011). ▪ Toolkits to develop palliative care programming in rural communities and LTCHs are available through the QPC-LTC project at Lakehead University and the NWO EOL Care Network.
<p>Human Capital</p> <p><i>“Adequate numbers of trained providers are available as per population based needs.”</i></p>	<ul style="list-style-type: none"> ▪ There is a core group of committed individuals with a passion for palliative care who are natural champions and mentors within their care settings and communities. ▪ Providers and organizations are flexible and often work together to go “above and beyond” their formal roles to see that clients and families are cared for. ▪ Providers from all disciplines and care settings express a desire to enhance their capacity to deliver palliative care through participation in ongoing education and skills development. ▪ Providers are comfortable using innovative technologies to facilitate communication, education, and increased access to care.
<p>Accountability</p> <p><i>“System level accountability is clearly defined and communicated.”</i></p>	<ul style="list-style-type: none"> ▪ Partners are willing to work with the North West LHIN to identify mechanisms to enhance accountabilities around palliative care.
<p>Technology</p> <p><i>“Leverage innovative use of technology to improve access to care”</i></p>	<ul style="list-style-type: none"> ▪ Innovative technologies are available to facilitate communication, education, and increased access to care. ▪ Multiple telemedicine programs such as tele-homecare, tele-visitation and tele-palliation are underway.

* These components are described in the System Design Framework that is endorsed in the Provincial Declaration (2011).

System Gaps

Community engagement and a quantitative analysis of the current state have identified the following gaps related to palliative care in the North West LHIN region. These gaps will form the basis of recommendations for the plan.

Table 5: System Gaps

Components of an Integrated System of Palliative Care	Gaps in the North West LHIN
Integration/Linkages/Education <i>“Sectors and services are linked by common practice, processes, structures, and education.”</i>	<ul style="list-style-type: none"> ▪ There has been no regional approach to palliative care planning and delivery in the North West LHIN. ▪ There is a lack of common definitions, tools, practices, and education standards for palliative care across the region, making it difficult to coordinate care across settings and communities. ▪ There are inconsistencies in the criteria used to determine access to palliative care programs and services. ▪ There is insufficient communication and coordination between First Nation community providers and external health care services.
Care Settings and Services <i>“A full continuum of care settings and services is in place as per population based needs.”</i>	<ul style="list-style-type: none"> ▪ There is no formal mechanism for 24/7 access to palliative care expertise. ▪ There are inconsistencies in the availability of palliative care programs and services at the LHH and IDN levels and timely access to care is a challenge. ▪ Access to timely, consistent home care is a challenge in many communities. ▪ There is limited availability of palliative care for individuals living in First Nations communities. ▪ There is limited availability of palliative care for populations such as children, individuals with developmental disabilities, and individuals who are homeless. ▪ Current palliative care programs and services do not adequately serve those with advanced chronic disease and longer illness trajectories. ▪ Caregivers do not feel sufficiently informed and supported to fully participate in the care of their loved ones.
Programs within Care Settings and Services <i>“In each care setting where individuals die, a palliative care program is developed.”</i>	<ul style="list-style-type: none"> ▪ There are varying levels of palliative care programming in hospitals, LTCHs, and community settings (including home care, assisted living, supportive housing, and group homes). ▪ The palliative approach to care is not embedded in the overall culture of care in many key settings. ▪ Individuals who may benefit from a palliative approach to care are not being identified consistently or early enough in the illness or disease trajectory.
Human Capital <i>“Adequate numbers of trained</i>	<ul style="list-style-type: none"> ▪ There is a general lack of understanding of the palliative approach to care amongst frontline staff in all care settings. ▪ There is limited access to ongoing clinical education,

<i>providers are available as per population based needs.”</i>	<p>experiential learning, and mentorship for providers at all levels of care.</p> <ul style="list-style-type: none"> ▪ There are a limited number of providers with training and experience in pediatric palliative care. ▪ There are a limited number of providers with training and experience in meeting the palliative care needs of First Nations individuals in a culturally relevant manner.
<p>Accountability</p> <p><i>“System level accountability is clearly defined and communicated.”</i></p>	<ul style="list-style-type: none"> ▪ There is little ongoing monitoring, reporting, and evaluation of palliative care programs and activities at the system level. ▪ The North West LHIN does not currently have targets or performance standards specifically linked to palliative care. ▪ Clearly defined roles and expectations for each type of setting and provider have yet to be developed. ▪ The NWO EOL Care Network has not had the capacity, accountability to the LHIN, or recognized authority to make sustainable changes to the palliative care system in Northwestern Ontario.
<p>Technology</p> <p><i>“Leverage innovative use technology to improve access to care”</i></p>	<ul style="list-style-type: none"> ▪ Technology is not utilized to its full potential, nor is it available in all settings where palliative care is delivered. ▪ Several pilot projects are underway; however evaluation, expansion and promotion of these projects is necessary.
<p>Culture</p> <p><i>“People accept death & dying as a normal part of life”</i></p>	<ul style="list-style-type: none"> ▪ There remains a stigma around accessing palliative and end-of-life care and a reluctance amongst the general population to discuss issues related to death and dying. ▪ There is no regional strategy for educating the public about the importance of Advance Care Planning.



Palliative Care in First Nations Communities

First Nations individuals make up a large part of the population in the North West LHIN. It is important to understand how the palliative care needs of individuals and families living in First Nations communities are met. While each First Nations community is unique, there are some commonalities of experience which are summarized below.

The care provided to individuals who are dying (and their families) in First Nations communities varies greatly by community. The federal government is the primary provider of health services on reserves. The Home & Community Care Program (HCCP) is funded by the First Nations & Inuit Health Branch (FNIHB) of Health Canada to assist people who have chronic and acute illnesses or disease to receive the care they need in their home or community. Palliative care is not funded as an essential service under the HCCP and therefore is only provided if budget and staff capacity allow. In some areas, a third party organization (Health Authority) has been created to deliver the HCCP to multiple First Nations communities. Additional health services are provided to First Nations individuals both on- and off-reserve by Aboriginal Health Access Centres, Indian Friendship Centres, and community Health Departments. The combination of multiple funding sources and different providers make it difficult to coordinate care for the First Nation communities.

“Due to relocation and travel costs patients are often unable to be with their families during palliation.”
~ A Provider

According to a survey of First Nation individuals living on reserve in Ontario, 87% of respondents felt that if services were available and adequate, their community members would choose to die at home (Brazil et al, 2012). However, anecdotal evidence from key informants across the North West LHIN suggests that very few (if any) expected home deaths occur in First Nations communities. Community members who are dying are often transferred off reserve to the nearest acute care setting or long-term care home to be cared for in their last days, weeks, or months of life. Health care providers who serve First Nations communities feel that while it is possible for community members to die at home if they choose, it is very difficult to accommodate this with existing resources.

There are additional challenges in accessing care close to home in remote First Nation communities in the Northern IDN. Health care providers report that individuals from fly-in communities must often remain in hospital in Sioux Lookout for simple care like dressing changes, OT/PT, and wound care that would ideally be provided back in their home community but is not currently available. This results in significant strain on the individual, their family and loved ones, and the health care system as a whole.

Communication between on- and off-reserve providers has been identified as a major issue that impacts the continuity of care and limits a community's ability to adequately plan and deliver the care required for an individual to remain at home. For example, there is often a gap in communication when a First Nation community member is discharged from a hospital to return to their home on reserve. Providers in First Nation communities report that they are often not informed when one of their community members is set to return home from the hospital, so they are left to scramble at the last minute to put the proper services in place to support the individual at home. At times First Nation community providers do not know who in their community is in need of care, as there is no clear transition or formal hand off from the hospital to the providers on-reserve.

Discharge planners at the hospitals often do not know who the appropriate contact is for each First Nation community in terms of arranging for home care once the individual is discharged. In some communities there may be multiple service providers who each play a role in coordinating home and community care. There is also concern for respecting the individual's privacy and maintaining confidentiality. Home & Community Care Program staff and workers in the Band's Health Department are often not included in the formal Circle of Care.

Both providers and First Nation individuals have also expressed concern that there is insufficient education and training in delivering culturally safe care. This is essential to ensure that appropriate care is being provided no matter where the individual is receiving it.

"Often the hospital setting is unable to accommodate traditional practices for First Nations individuals who are unable to return to their community to pass." ~ A Provider

Despite these challenges, the End-of-Life Care in First Nations (EOLFN) project at Lakehead University has demonstrated that high quality palliative care can be delivered in First Nation communities by using a community development approach to engage partners both on- and off-reserve in seeking solutions to local needs. The findings of the EOLFN project will be used to provide guidance on how to proceed with improving palliative and end-of-life care for all First Nations communities.



Innovative Use of Technology

The use of technology in Northwestern Ontario has great potential to increase access to key palliative and end-of-life care resources and enhance the capacity of individual providers by allowing them to see clients in a more timely and efficient manner. Technology can also be used to connect frontline providers from across the region to palliative care expertise and to enhance educational opportunities available to providers. Several projects are underway to leverage the use of technology to improve access to specialist palliative care within the North West LHIN.

Tele-Palliation

TBRHSC is working with SJCG on a Tele-Palliation Pilot project to evaluate the use of tablets with Ontario Telemedicine Network (OTN) technology in the homes of clients. This technology is used to facilitate virtual appointments with palliative care physicians. Planned appointments through video connection within the individual's home eases the client and family's fears and reduces the negative consequences associated with isolation, travel, and waiting for appointments. Early reports suggest that clients highly value this service as they are able to stay at home and use the saved time and energy for living life. Preliminary results show many positive outcomes, with a high level of satisfaction reported by both physicians and the clients and families.

"I am enjoying being able to see the doctor this way. My life is better as I don't have to wait in the doctor's office" ~ A Client

Telehomecare

The telehomecare program at TBRHSC serves clients with Heart Failure and COPD. This population is medically fragile with a high level of complex care needs. The program has determined that >75% of their clients would benefit from a palliative approach to care. The telehomecare program places equipment in the client's home that allows the client to assess his/her vital signs on a daily basis and submit them to an NP who is virtually monitoring the client's condition. The NP can then make adjustments to the client's care plan based on the data received. Clients and caregivers report that participation in this program has increased the sense of control clients have over their condition and the care they receive. The knowledge that an NP is responding to changes in condition in a timely manner reduces the stress of both the client and caregiver. The telehomecare program has demonstrated that technology can be used to support individuals with complex care needs in their own home.

Caregiver Support

The Telemedicine Nursing program at SJCG has partnered with Dryden Regional Health Centre to run a support group for informal caregivers across the region via OTN. Anyone who would like to access this support can attend monthly meetings from an OTN site in their home community. There is the potential to use this technology to offer further services to caregivers, such as grief and bereavement counseling following the death of a loved one. This could be particularly beneficial for caregivers living in communities where there is limited grief and bereavement support, or where they may be uncomfortable accessing this service from someone they know, which is often the case in smaller rural communities.

Tele-Visitation

Tele-Visitation uses videoconferencing technology to allow patients in a hospital setting to connect virtually with their loved ones who are unable to visit them in person. In the North West LHIN, tele-visitation is supported by both TBRHSC and SJCG's Telemedicine Nursing program. Clients have been able to utilize this service to connect with loved ones from out of town as they near the end of life. Clients and their families express delight in being able to visit when they

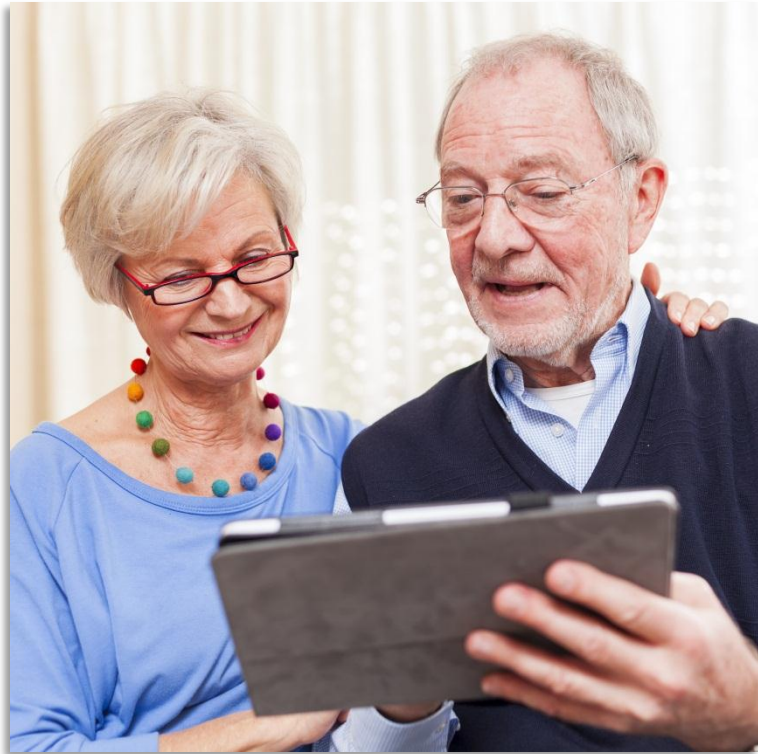
otherwise may not have been able to see each other face to face. TBRHSC also collaborates with SJCG to promote tele-visitation between loved ones who are admitted at both facilities via access to OTN on a laptop or tablet. For example, one woman was in St. Joseph's Hospice Unit for end of life care while her husband was admitted to TBRHSC and unable to visit her in person. The tele-visitation service allowed the couple to connect "face to face" through virtual means, which was of great benefit to both clients.

Education

Both CERAH and NOSM offer palliative care education sessions using OTN technology. To increase access to palliative care education for providers in the region, CERAH plans to increase the number sessions offered via OTN in the future. The use of OTN also allows sessions to be recorded and archived, so providers can access presentations and materials at a later date more convenient for them.

Several small pilot projects have been conducted using simulation technology to deliver palliative care education to frontline providers. The SimLab at Lakehead University's School of Nursing is set up to simulate a typical room in a hospital or long-term care home. A life-like mannequin serves as the "patient" and providers are guided through a scenario in which they must interact with the patient/mannequin and respond to its needs, allowing them to apply skills and techniques that they have previously learned in a classroom setting. Research affiliates at CERAH and Lakehead University are pursuing opportunities to conduct further research on how to use this technology to provide experiential learning opportunities to providers. A mobile SimLab and other simulation equipment is available to offer this unique educational experience to providers in the region.

Overall, technology can be a great enabler to improve access to palliative care services, education and training. However, it must be noted that many First Nation communities do not currently have access to telemedicine, which limits their ability to fully benefit from the use of technology. With many different organizations piloting the use of technology in Northwestern Ontario it is important to monitor and measure the outcomes of these initiatives and consider opportunities for expansion as they prove effective.



4.0 Desired Future State

“All of my care providers will work together with me and my family to support our quality of life throughout this journey and respond to our needs in a coordinated way.”

The value statement created by clients and caregivers in the North West LHIN and the Provincial Declaration both challenge the system to improve client and caregiver experience through the delivery of high quality palliative care across settings and providers.

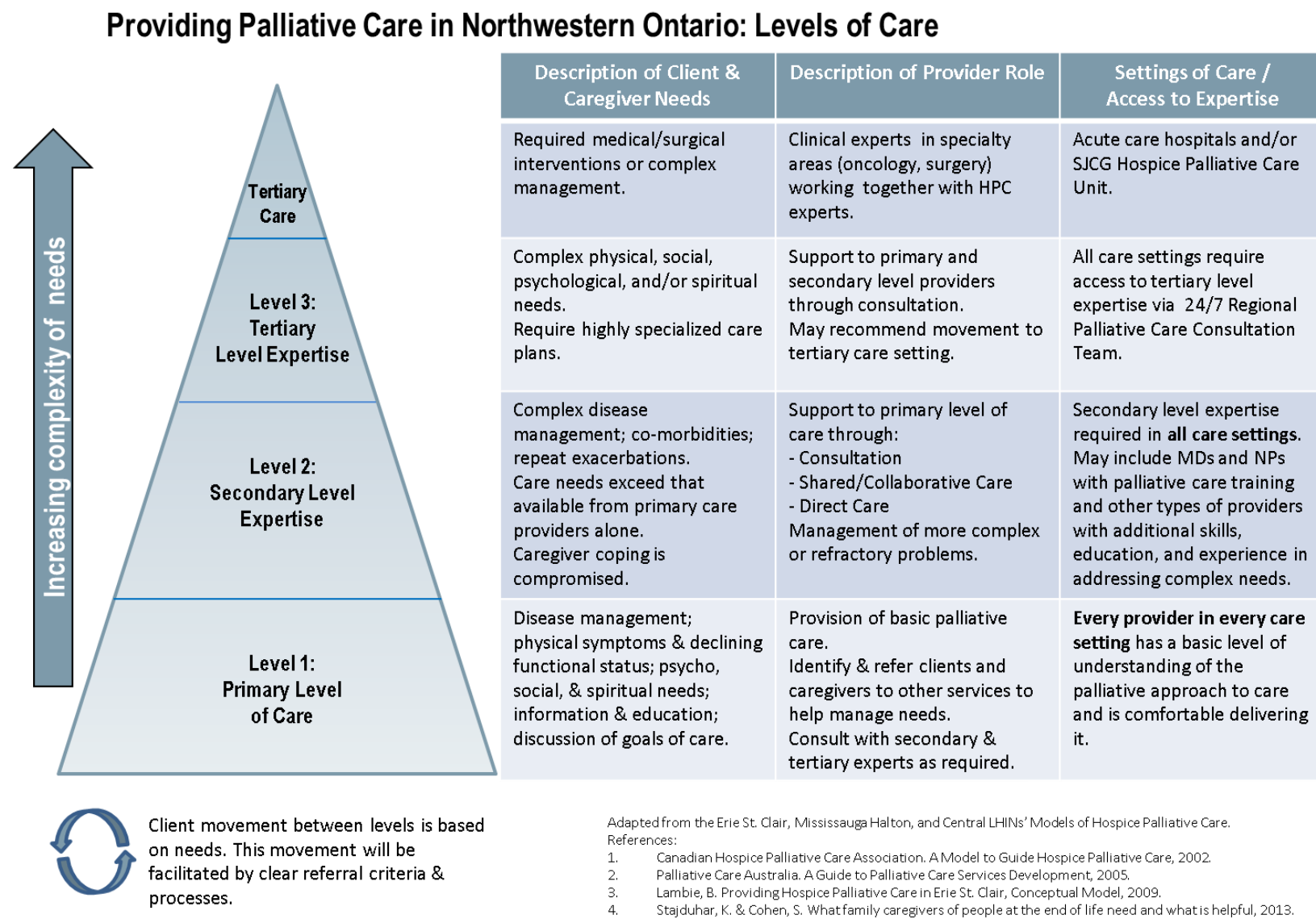
The vision for Northwestern Ontario is to create a system of care that will serve all individuals who could benefit from a palliative approach to care, regardless of prognosis or diagnosis. The system will respond to the needs of not only the individual but their family, friends, and caregivers as well. A full continuum of care will be available from the initial diagnosis to the period of bereavement following death.

All individuals, regardless of their care setting, will receive care that is person and family-centred, focused on enhancing quality of life, and delivered by an interdisciplinary team. The individual and family's needs will be identified early on and they will be engaged as partners in all care planning and decision making.

Model of Care

In order to achieve this vision, palliative care in the North West LHIN will be developed according the model on the following page.

Figure 5: Providing Palliative Care in Northwestern Ontario – Levels of Care



This model reflects the public health approach to palliative care by supporting the provision of a palliative approach in all care settings by all providers, including caregivers and volunteers. It recognizes that every provider has a responsibility for understanding and delivering a palliative approach to care to the clients and families they serve. It also seeks to involve citizens and community groups in providing support to individuals who are dying and their families.

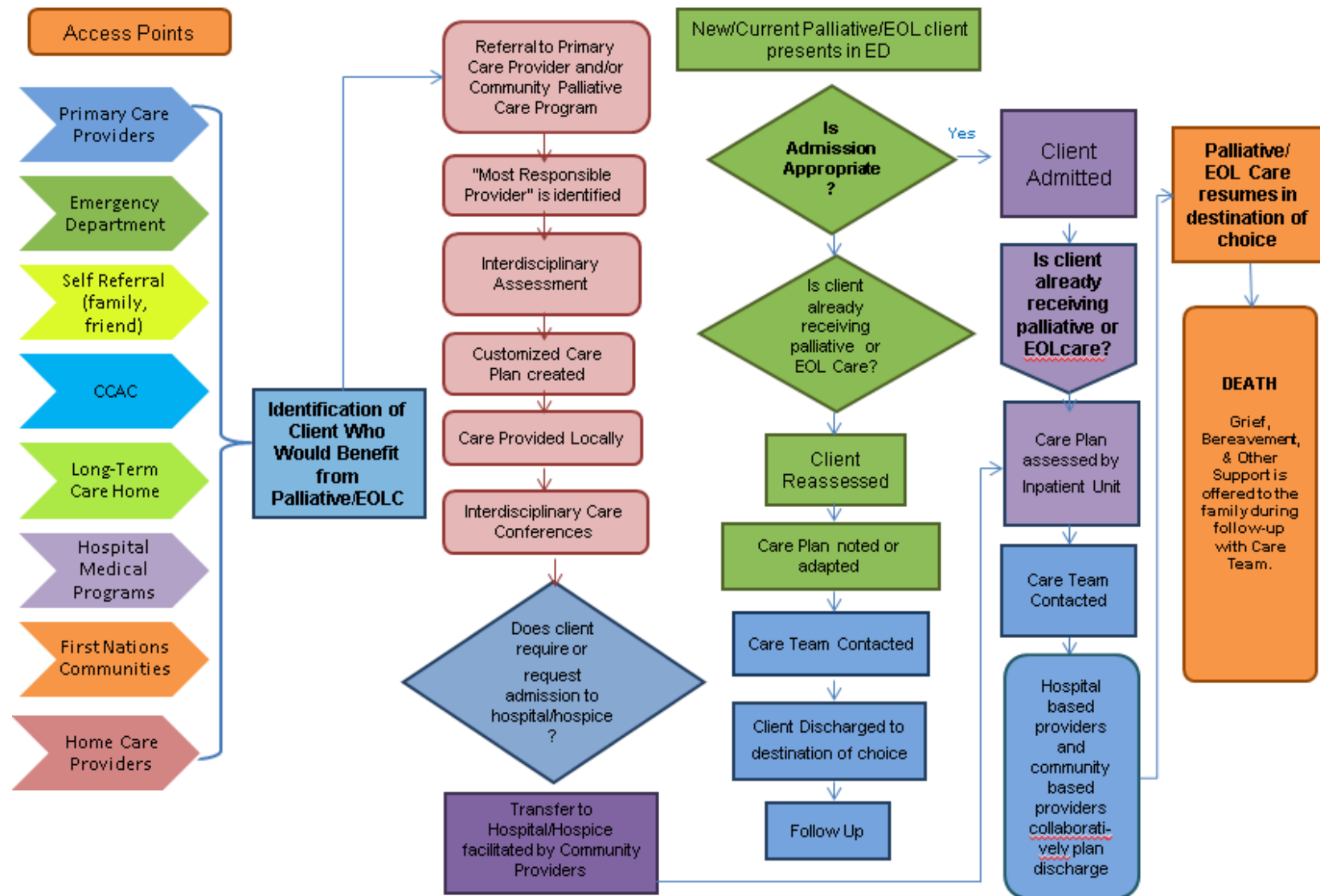
This model focuses on 1) building a base level of knowledge and understanding of palliative care at the primary level of care, and 2) linking the primary level providers to palliative care expertise and services when their clients' needs become more complex.

In the North West LHIN, primary care providers will be supported to deliver the majority of palliative care using an interdisciplinary team approach and working in collaboration with secondary and tertiary level palliative care experts when required. These experts will have specific education and training in palliative care and will provide support and consultation to primary care providers to manage complex issues. 24/7 access to palliative care expertise will be organized regionally to support the delivery of high quality care at the LHH level. A clear understanding of how the different levels of providers work together will be developed.

Journey Map – Desired Future State

While the model of care describes how palliative care will be developed at the system level, the map on the following page depicts how the individual and family will experience care in the desired future state. It is a high level rendering of a typical journey in the North West LHIN and does not necessarily reflect unique considerations by individual or community.

Figure 6: Future State Patient Journey Map – Palliative/End-of-Life Care



In the desired future state, there is a standardized approach to palliative care across the North West LHIN. Individuals and families who could benefit from a palliative approach to care are identified early on by any one of the providers they come into contact with. A standardized assessment and screening tool is used across care settings to identify those who should be offered a palliative approach to care. Staff are trained in how to use this screening tool and are aware of the follow-up protocol. Palliative care programming is available in every care setting. Members of the individual's interdisciplinary care team are identified and are aware of each other's role in the care of the individual and family, and the specific services each is providing. The individual and family feel informed and supported as members of their care team. The individual and family are familiar with their care team, what each provider's role is, and where to go or who to contact to get their various needs addressed.

Members of the interdisciplinary care team have 24/7 access to palliative care expertise for consultation and additional support. A shared care approach is utilized in complex cases where primary care providers are supported by palliative care experts in the delivery of care. Ongoing education and training is available to all members of the interdisciplinary care team.

A "Most Responsible Provider" (MRP) is assigned as the key contact for the individual and family. The MRP will facilitate communication and coordination with the other providers who are members of the interdisciplinary care team. The MRP may vary depending on the community and the individual and family's needs. The MRP could be the family physician, nurse practitioner, CCAC Care Coordinator, or Home & Community Care Program Coordinator.

Health Links is leveraged to promote care coordination and communication amongst providers. The individual and family participate in a comprehensive assessment and development of a customized care plan to meet their goals and needs. The care plan will encompass all settings in which the individual and family receives care, and will travel with them as they transition between settings. Appropriate community supports are identified to allow the individual to remain in their home for as long as possible. The care plan is continually updated as necessary, through care conferences with the individual and family and their interdisciplinary care team. For First Nation individuals, the care plan identifies considerations for culturally appropriate care and coordination between on- and off-reserve providers.

While the construction of a standalone residential hospice is not recommended at this time, a full continuum of care will be in place to meet the needs of the individual and family throughout their journey. Hospice-like spaces will be available in existing facilities to ensure privacy and comfort for individuals and families at the end of life. Care continues to be offered to family and loved ones following the death of the individual.

When possible, technology will be used to facilitate timely, virtual access to care and communication amongst members of the interdisciplinary care team.

All care settings and providers will participate in continuous quality improvement initiatives to ensure a high quality experience for every individual and family.

Bridging the Gaps to Future State – Recommendations

To achieve this desired future state, the North West LHIN will leverage its existing strengths to address the identified gaps and create a comprehensive system of palliative care across the region. The following recommendations are made to guide the transition from the current state to the desired future state. These recommendations will form the basis for all future work.

Table 6: Linking Gaps and Recommendations

Components of an Integrated System of Palliative Care	Gaps in the North West LHIN	Recommendation(s)
Integration/Linkages/ Education <i>“Sectors and services are linked by common practice, processes, structures, and education.”</i>	<ul style="list-style-type: none"> There has been no regional approach to palliative care planning and delivery in the North West LHIN. There is a lack of common definitions, tools, practices, and education standards for palliative care across the region, making it difficult to coordinate care across settings and communities. There are inconsistencies in the criteria used to determine access to palliative care programs and services. There is insufficient communication and coordination between First Nation community providers and external health care services. 	Establish a standardized approach to care across settings and providers.
Care Settings and Services <i>“A full continuum of care settings and services is in place as per population based needs.”</i>	<ul style="list-style-type: none"> There is no formal mechanism for 24/7 access to palliative care expertise. There are inconsistencies in the availability of palliative care programs and services at the LHH and IDN levels and timely access to care is a challenge. Access to timely, consistent home care is a challenge in many communities. 	<p>Develop a shared care model for palliative and end-of-life care whereby primary level providers deliver the majority of care with back-up support from secondary and tertiary level experts.</p> <p>Provide 24/7 access to tertiary level expertise for providers across the North West LHIN.</p> <p>Explore opportunities to improve access to a full continuum of care settings and services across the North West LHIN.</p> <p>Ensure that adequate community supports are available across the North West LHIN to allow individuals to experience a good</p>

	<ul style="list-style-type: none"> There is limited availability of palliative care for individuals living in First Nations communities. Current palliative care programs and services do not adequately serve those with advanced chronic disease. Caregivers do not feel sufficiently informed and supported to fully participate in the care of their loved ones. 	<p>quality of life and death at home.</p> <p>Work with First Nation communities and organizations to provide access to culturally appropriate palliative care services and support for their members.</p> <p>Provide quality, timely palliative and end-of-life care to those with advanced or progressive chronic disease.</p> <p>Explore options for the creation of hospice-like spaces in key care settings where people die. The development of a standalone 10-bed residential hospice will not proceed at the time of this plan given current fiscal constraints and the unique needs of the North West region.</p> <p>Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision.</p>
<p>Programs within Care Settings and Services</p> <p><i>"In each care setting where individuals die, a palliative care program is developed."</i></p>	<ul style="list-style-type: none"> There are varying levels of palliative care programming in hospitals, LTCHs, and community settings (home care, assisted living, supportive housing, group homes). The palliative approach to care is not embedded in the overall culture of care in many key settings. Individuals who may benefit from a palliative approach to care are not being identified. 	<p>Palliative care programming will be available in every health care setting.</p>
<p>Human Capital</p> <p><i>"Adequate numbers of trained providers are available as per population based needs."</i></p>	<ul style="list-style-type: none"> There is a general lack of understanding of the palliative approach to care amongst frontline staff in all care settings. There is limited access to ongoing clinical education, experiential learning, and mentorship for providers at all levels of care. There are a limited number of providers with training and experience in pediatric palliative care. 	<p>Ensure that palliative care education is available and accessible for all providers.</p>

	<ul style="list-style-type: none"> There are a limited number of providers with experience in meeting the palliative care needs of First Nations individuals in a culturally relevant manner. 	
<p>Accountability</p> <p><i>“System level accountability is clearly defined and communicated.”</i></p>	<ul style="list-style-type: none"> There is little ongoing monitoring, reporting, and evaluation of palliative care programs and activities at the system level. The North West LHIN does not currently have targets or performance standards specifically linked to palliative care. Clearly defined roles and expectations for each type of setting and provider have yet to be developed. The EOL Care Network has not had the capacity, accountability to the LHIN, or recognized authority to make sustainable changes to the palliative care system in Northwestern Ontario. 	Measure, monitor, and evaluate overall system performance.
<p>Technology</p> <p><i>“Leverage innovative use technology to improve access to care”</i></p>	<ul style="list-style-type: none"> Technology is not utilized to its full potential. Several pilot projects are underway; however expansion of these projects is necessary. 	Support the use of innovative technologies to provide access to 1) consultation and support, and 2) education and training.
<p>Culture</p> <p><i>“People accept death & dying as a normal part of life”</i></p>	<ul style="list-style-type: none"> There remains a stigma around accessing palliative and end-of-life care and a reluctance amongst the general population to discuss issues related to death and dying. 	Increase public awareness and dialogue on palliative care.

These recommendations will be implemented through the creation of a Regional Palliative Care Program, as described in the following section.

5.0 A Regional Palliative Care Program for Northwestern Ontario

Description

A Regional Palliative Care Program will be created in the North West LHIN to provide the leadership and oversight to develop the palliative care system across Northwestern Ontario and act on the recommendations of this plan.

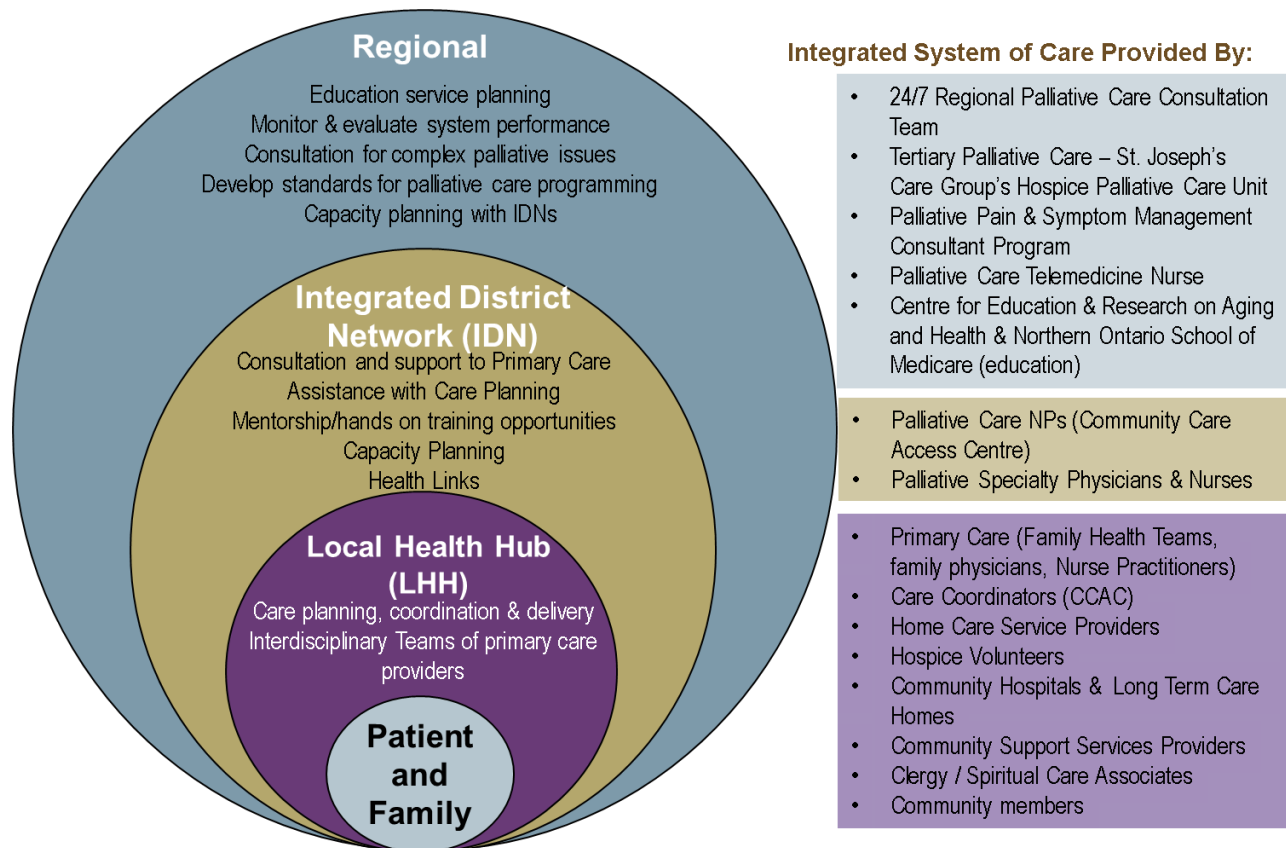
The Regional Program will:

- Work with the North West LHIN to implement the recommendations of this plan;
- Ensure that care is based on evidence and leading practice;
- Strengthen the delivery of the palliative approach to care by primary care providers and link the primary level of care to secondary and tertiary level palliative care expertise;
- Support collaboration and capacity building at the HSP, LHH, IDN, and Regional levels;
- Identify local and regional service gaps, strengths, and priorities;
- Lead the development of a standardized approach to palliative and end-of-life care across the region;
- Collaborate with Health Links to enhance client and caregiver experience and facilitate integrated care delivery;
- Monitor, evaluate, and report on system performance and client and caregiver outcomes; and
- Promote a public health approach to palliative care that engages citizens and communities to support dying individuals and their families.

Specifically, the Regional Program will provide support to HSPs and LHHs by:

1. Developing standards, policies and protocols, common definitions and tools, and education/staff training materials that can be adapted to strengthen their programming.
2. Guiding them through the process of program planning, implementation, and evaluation using a community capacity development approach.
3. Helping them identify quality improvement projects that can be piloted in their care settings and communities using Continuous Quality Improvement (CQI) methodology.

The following diagram depicts the activities that the Regional Program will support and work to strengthen at each level of planning and implementation.

Figure 7: North West LHIN Palliative Care Program Service Delivery Model

Structure, Governance & Accountability

Historically, the NWO EOL Care Network has not had the capacity, accountability to the LHIN, or recognized authority to make sustainable changes to the palliative care system in Northwestern Ontario. Therefore, a new approach is proposed – the transition of the NWO EOL Care Network to a Regional Palliative Care Program. The recommended governance structure for the Regional Palliative Care Program is presented below.

Each Community Palliative Care Team will be made up of representatives of the community's care providers. Community Palliative Care Teams will include representation from all disciplines and organizations involved in supporting individuals who are dying and their families, including, but not limited to, home care, primary care, hospitals, LTCHs, hospice volunteers, community support services, funeral homes, emergency medical services (EMS), and First Nations communities and organizations. The make up of the Community Palliative Care Teams may vary by LHH, building on the existing strengths and resources of each community.

The Community Palliative Care Teams will provide the leadership to implement recommendations from the Regional Program at the LHH level. With the support of the Regional Palliative Care Program, the Community Palliative Care Teams will use CQI methodology to plan, implement, and evaluate initiatives to address specific gaps in their communities.

Performance Measurement

All 14 LHINs have collectively identified outcomes that are to be achieved through the implementation of their regional palliative care plans. The work of the Regional Program will contribute to the achievement of these outcomes, which are presented in the table below.

Table 7: Palliative Care Metrics

METRIC (patients with ICDA-CA code Z51.5 – palliative care)	NW LHIN Baseline (3-year average 2011-13)	TARGET (2017-18)
Total # of hospital days attributed to palliative care.	18,038	10% reduction = ▼ 1804 days (to 16,234 days)
% of patients discharged home with support	24.9%	▲
% of patients discharged home without support	6.4%	▼
Average total length of stay (LOS)	15.3 days	▼
% of patients who died in acute care hospital	44.9%	▼
# of ALC days	4.4 days	▼

It is recognized that progress towards these system level outcomes will be slow but deliberate. Historically, there have been inconsistencies in the collection of this data which may skew the initial reporting of outcomes. Process measures and outcomes will be identified to track overall progress on the implementation of this plan.

At the time of writing this plan, significant work on data and performance indicators was still underway at the provincial level. Additional indicators are expected to be developed which will include outcomes related to client and caregiver experience. These indicators will be incorporated in the plan as they are developed.

Implementation Plan

The Regional Palliative Care Program will be responsible for overseeing the implementation of this plan and its recommendations.

The initial work will focus on transitioning from an EOL Care Network to a Regional Palliative Care Program. By March 31st, 2015, a Host Agency for the Regional Program will be identified and accountability to the North West LHIN will be defined. The creation of the Regional Program will be communicated to all HSPs. Terms of Reference for an Advisory Committee will be created and its members will be selected.

In year one of the Regional Program (2015-16), priority projects will be identified by the Advisory Committee, task groups will be established, and detailed work plans created. The Regional Program will initiate work towards establishing a Community Palliative Care Team in every LHH using a process of community capacity development as outlined in the model developed by Kelley et al (2011).

Recognizing the importance of engaging clients and caregivers in system design, opportunities for client and caregiver participation will be identified as implementation proceeds. The Regional Program Advisory Committee will seek input from clients and caregivers on a regular basis.

At the time this plan was written, provincial planning was still underway. Where appropriate, the Regional Program will work in conjunction with the provincial HPC Steering Committee and other partners to achieve common goals. In some cases, the need to align regional work with provincial initiatives may change and/or delay the completion of deliverables by the Regional Program. An Auditor General's report on palliative care is expected by January 1st, 2015, which may lead to additional recommendations needing to be addressed by the North West LHIN and Regional Program.

The implementation activities outlined below will commence once the Regional Palliative Care Program has been established. Continuous quality improvement (CQI) methodology will be used to plan, implement, and evaluate all initiatives.

Table 8: Three Year Implementation Plan

RECOMMENDATION 1: Establish a standardized approach to care across settings and providers			
Initiatives	Activities	Deliverables	Outcomes
Establish a common definition of palliative care amongst all care providers.	<p>Year one: Develop a common definition of palliative care for the region and communicate it to all health service providers.</p> <p>Develop an education module to introduce the palliative approach to care to staff.</p> <p>Year two and beyond: Completion of the education module by staff in all hospitals, LTCHs, home care, and community support service agencies, using a phased approach.</p>	<p>A standard definition of palliative care is established across the LHIN.</p> <p>A standard introductory education module for palliative care is created.</p> <p>The education module is delivered in all hospitals, LTCH, home care, and community support service agencies.</p>	<p>Increased knowledge & understanding of palliative care amongst all providers.</p> <p>Consistent and standardized education across all settings and providers.</p>
Adapt and test tools and protocols for palliative care screening and assessment for use by all care providers.	<p>Year one: Form a Task Group to review existing tools and make recommendations on which tools to pilot for use in the North West LHIN.</p> <p>Year two: Pilot the recommended screening and assessment tool(s) in several care settings in each IDN (e.g. hospital, LTCH, FHT, First Nations Home & Community Care Program).</p> <p>Year three and beyond: Refine tool(s) based on results of pilot projects and introduce to remaining IDNs.</p>	<p>Task Group is established. Standardized screening and assessment tool(s) are selected.</p> <p>Pilot projects are completed in two IDNs.</p> <p>Tool(s) is refined.</p>	<p>Earlier identification of individuals who would benefit from a palliative approach to care.</p> <p>Improved integration and continuity of care across settings and jurisdictions.</p>
Establish a Palliative Care Pathway in each LHH.	<p>Year one: Develop a sample care pathway that can be adapted at the LHH level.</p> <p>Years one and two: Identify lead(s) in each LHH to facilitate the work with local partners to create a care pathway for their community.</p> <p>Year three and beyond: Implement the Palliative Care Pathway in each LHH.</p>	<p>Sample Palliative Care Pathway is created.</p> <p>Local leads for palliative care in each LHH are identified.</p> <p>A clearly defined Palliative Care Pathway is implemented in each LHH.</p>	<p>Improved integration and continuity of care across settings and jurisdictions.</p> <p>Clear roles and responsibilities for all care providers.</p> <p>Improved client & caregiver experience.</p>

Develop a collaborative care planning process and supporting tools in conjunction with Health Links and other initiatives.	Year one: Identify elements for a collaborative care plan for palliative care. Years two and three: Customize Health Link's collaborative care planning process and tools for palliative care. Test the process and tool leveraging other initiatives (such as the Medically Complex Demonstration Project).	A collaborative care planning process and supporting tools for clients requiring a palliative approach to care is developed.	Delivery of palliative care through an integrated, interdisciplinary team approach. Enhanced communication and coordination amongst providers. Improved client and caregiver experience.
Standardize language & content in palliative care education and training materials.	Year one: Create an inventory and analysis of existing palliative care education & training for staff. Year two: Develop a standardized education module for palliative care as described in 1A.	Inventory of current palliative care education & training materials and content analysis is completed.	Consistent and standardized education across settings and providers.

RECOMMENDATION 2: Develop a shared care model for palliative and end-of-life care whereby primary level providers deliver the majority of care with back-up support from secondary and tertiary level experts

Initiatives	Activities	Deliverables	Outcomes
Engage with primary care providers to identify their needs regarding access to palliative care expertise and introduce the shared care approach.	Year one: Create a communication & engagement strategy for primary care providers. Year two and beyond: Carry out activities outlined in the strategy.	Primary Care engagement strategy is developed. A report on primary care engagement activities and key findings is completed.	Primary Care sector is supportive of the shared care approach. Increased capacity in the Primary Care sector to deliver palliative care.
Identify existing secondary and tertiary level palliative care experts in the North West LHIN.	Year one and two: Create a list of existing and potential secondary and tertiary level palliative care experts in the region. Assess the availability of palliative care experts and their interest in providing consultation, education, training, and mentorship.	List of interdisciplinary secondary and tertiary level experts is created and assessment of their capacity is completed.	Increased access to interdisciplinary palliative care expertise.

	Year two: Identify education and training needs of potential experts. Identify options for training more palliative care experts.	A plan for training additional experts is developed.	
In collaboration with Health Links, develop a shared care model to coordinate care amongst primary care providers and palliative care experts for clients with complex needs.	Year one: Leveraging the Medically Complex Demonstration Project, develop and pilot the use of a shared care model for individuals with advanced CHF and COPD. Year two: Evaluate the shared care model and assess opportunities for expansion.	A shared care model is developed. The shared care model is implemented. An evaluation report and options for expansion is completed.	Primary care providers are supported to deliver high quality palliative care to their clients. Delivery of palliative care through an integrated, interdisciplinary team approach. Clear roles and responsibilities for all care providers.

RECOMMENDATION 3: Provide 24/7 access to tertiary level expertise for providers across the North West LHIN

Initiatives	Activities	Deliverables	Outcomes
Create a regional Palliative Care Consultation Team (PCCT) to provide clinical consultation and support 24/7.	Year one: Develop a model for 24/7 access to PCCT leveraging the palliative care experts identified in recommendation 2. Identify resources required to provide 24/7 coverage and match against existing resources from partners. Year two: Establish formal agreements with participating partners and launch the PCCT. Communicate information about the PCCT to all HSPs across the region. Years two and three: Conduct an evaluation the PCCT.	Model for implementation of 24/7 PCCT is developed. Partnership agreements are signed. 100% of hospitals, LTCHs, and FHTs receive information on the PCCT & how to access it. An evaluation report is completed.	Increased access to palliative care expertise. One clear access point for palliative care expertise available 24/7. Primary care providers supported to deliver high quality palliative care to their clients. Continuous quality improvement.

RECOMMENDATION 4: Palliative care programming will be available in every health care setting

Initiatives	Activities	Deliverables	Outcomes
Develop standards and guidelines for palliative care programming in each type of care setting. (e.g. policies on Advanced Care Directives, mandatory staff education, access to palliative care expertise).	<p>Year one: In conjunction with provincial work and the work of the QPC-LTC project, develop standards and guidelines for palliative care programming for hospitals and LTCHs. Review with a Francophone lens prior to implementation.</p> <p>Year two: Communicate the standards & guidelines to hospitals and LTCHs. Assess current palliative care programming in all hospitals and LTCHs. Create supporting materials to assist with meeting the standards. Work with hospitals & LTCHs to facilitate change.</p> <p>Years three and beyond: Implement the standards & guidelines in all hospitals & LTCHs. In conjunction with provincial work, develop & implement standards for other sectors such as Home Care.</p>	<p>Standards & guidelines for hospitals & LTCHs are developed.</p> <p>Self-assessments completed by 100% of hospitals and LTCHs.</p> <p>Supporting materials for hospitals & LTCHs are developed.</p> <p>100% of hospitals & LTCHs demonstrate progress towards meeting standards & guidelines. Standards & guidelines for other sectors are developed.</p>	<p>Strengthened delivery of palliative care in hospitals.</p> <p>Strengthened delivery of palliative care in long-term care homes.</p> <p>Capacity building within key care settings.</p>

RECOMMENDATION 5: Explore opportunities to improve access to a full continuum of care across the North West LHIN

Initiatives	Activities	Deliverables	Outcomes
Define 1) what services and care settings are needed to provide a full continuum of care; and 2) what level they will be made available (e.g. LHH, IDN, and regional).	<p>Year one: In conjunction with provincial work, clearly articulate the continuum of care services that should be available. Create an inventory of current palliative care services and settings in the North West LHIN and assess their capacity.</p> <p>Year two: Conduct an analysis of gaps in the continuum of care at the LHH, IDN, and</p>	<p>An inventory of services across the continuum of care is created. A demand/capacity analysis is conducted.</p> <p>A gap analysis is completed.</p>	Consistent access to palliative care across all population groups & geographies.

	regional levels.		
Develop unique, localized solutions to bridge the gaps identified in the current continuum of care.	Year two and beyond: Build on existing resources through collaboration & partnerships to meet the needs identified (e.g. grief & bereavement support).	New cross-sector partnerships are established.	Consistent access to palliative care across all population groups & geographies.

RECOMMENDATION 6: Ensure that adequate community supports are available across the North West LHIN to allow individuals to experience a good quality of life and death at home

Initiatives	Activities	Deliverables	Outcomes
Engage, collaborate, and partner with the CCAC and community providers to improve the support that individuals and families receive at home.	Year one: Complete an inventory and analysis of current programs and services to support individuals & families in the community. Identify gaps at the LHH and IDN level.	An inventory & analysis of current supports is completed.	Improved client & caregiver experience. Improved access to caregiver supports.
Identify and evaluate means of delivering home care in communities where there is a lack of home care providers to meet the needs of clients and families.	Year one and beyond: Working with the CCAC & other partners, identify, implement, and evaluate innovative solutions to improve access to home care.	Implementation and evaluation plans are developed.	Improved access to care in the community.
Improve timely access to equipment and medication in Local Health Hubs.	Year one and two: Identify and pilot solutions to ensure timelier access to medication and equipment (e.g. palliative care symptom management kits).	Palliative Care Symptom Management Kits are piloted in 2 communities.	Improved pain & symptom management. Improved client and caregiver experience.

RECOMMENDATION 7: Collaborate with First Nations communities and organizations to improve access to culturally appropriate palliative care services and support for their members			
Initiatives	Activities	Deliverables	Outcomes
Collaborate with the EOLFN project and Nootkamegwanning First Nation to increase access to palliative care on reserve.	Year one: Pilot increased access to palliative care support in one First Nations community. Evaluate the effectiveness of this model. Year two: Consider options for expansion at the completion of the pilot.	Progress reports and final evaluation are completed. Options for continuation/expansion are developed.	Improved access to palliative care for First Nations individuals and families.
Review all definitions, tools, and protocols developed by the Regional Program with a First Nations lens prior to implementation.	Year one and beyond: Seek ongoing consultation & input from First Nations stakeholders regarding activities of the Regional Program.	Engagement with First Nations stakeholders is completed. All products of the Regional Program are reviewed with a First Nations lens prior to implementation.	Increased access to culturally safe care. A Regional Program that is inclusive of First Nations communities & providers.
Increase access to education for staff in providing culturally safe care to First Nations individuals.	Year one: Review existing education materials on culturally safe care and share with HSPs.	Inventory of educational materials for culturally safe care is created.	Increased access to culturally safe care.
Facilitate work between hospitals and First Nations communities to develop, implement, and evaluate a discharge protocol for First Nations clients returning home after hospitalization.	Year one: Develop a sample discharge protocol which is aligned with work currently being done on common discharge plans and the EOLFN project. Years two and three: Adapt & pilot the discharge protocol in each IDN. Year three and beyond: Adapt & implement the discharge protocol in all hospitals.	Sample discharge protocol is developed. Pilot project is implemented in one hospital & First Nations community per IDN.	Enhanced navigation and coordination of care. Improved integration and continuity of care across settings and jurisdictions.
Improve utilization of virtual technology by providers in First Nations communities.	Year one: Meet with partners to discuss opportunities for increasing the use of virtual technology with First Nations providers.	One meeting with partners is held.	Increased awareness amongst First Nations community providers regarding the use of virtual technology to deliver care.

RECOMMENDATION 8: Provide quality, timely palliative and end-of-life care to individuals with advanced or progressive chronic disease

Initiatives	Activities	Deliverables	Outcomes
Explore interim solutions to increase supports for individuals who have complex needs but do not require admission to a tertiary setting.	Year one: Form a Task Group for the City of Thunder Bay IDN. Evaluate existing programs and services that service this population. Explore and identify care options for this population. Year two and beyond: Implement and evaluate care options for this population.	A Task Group is established. Analysis of existing services and options is completed. An implementation & evaluation plan is developed.	Improved client and caregiver experience.
Work with existing CDM programs and Health Links to identify opportunities for integration with palliative care services and supports.	Year one: Support the implementation of the Medically Complex Demonstration Project and leverage resulting work. Establish partnerships with other CDM programs.	Partnerships with CDM programs are established. The palliative care education module is shared with CDM programs.	Clinical integration of palliative care services with chronic disease management programs.

RECOMMENDATION 9: Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision

Initiatives	Activities	Deliverables	Outcomes
Improve access to information for individuals, families, and caregivers on palliative care and the supports available to assist them.	Year one: Review existing caregiver support materials with input from caregivers. Year two: Create an online library of caregiver support materials and promote it to individuals, families, caregivers, and providers.	Review of existing materials is completed. Online library of resources and services is created. A communication strategy for promotion of online library is developed.	Increased information provided to caregivers.
Work with Community Palliative Care Teams to identify local supports that are available to caregivers in each LHH.	Year two and beyond: Create information packages on caregiver supports for each LHH.	By the end of Year two, 5 LHHs have created information packages for caregivers.	Increased information provided to caregivers.

Improve access to supports for caregivers (e.g. education & training, grief and bereavement services).	Year two: Complete an analysis of the demand for current caregiver support programs and services and identify opportunities for expansion.	Analysis of current services & opportunities for expansion is completed.	Improved access to caregiver supports. Improved client and caregiver experience.
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RECOMMENDATION 10: Explore options for the creation of hospice-like spaces in key care settings where people die (The development of a standalone 10-bed residential hospice will not proceed at the time of this plan given current conditions and the unique needs of the North West region)

Initiatives	Activities	Deliverables	Outcomes
Work with hospitals to establish clear, consistent criteria for self-designated palliative care beds and report on utilization.	Year two: Form a Task Group to create a standard set of criteria for palliative care beds and identify a mechanism for reporting on bed utilization. Year three: Collect utilization data for the self-designated palliative care beds from hospitals. Complete an analysis of the data and determine the need for additional hospice-like spaces.	A Task Group is established. A standard set of criteria for palliative care beds is developed & implemented. A reporting mechanism is established. A demand/capacity analysis is conducted.	Strengthened delivery of palliative care in hospitals. Consistent access to tertiary level palliative care.
Clearly define the population to be served by the HPCU at SJH and its role in the continuum of care.	Year one: Work with SJCG and other system partners to review and revise the criteria and assessment process for admission to the HPCU. Year two: Complete an analysis of individuals who are referred to tertiary level palliative care and evaluate the HPCU's new referral process and admission criteria.	A clear referral process and admission criteria is established for the HPCU beds at SJH. A demand/capacity analysis is conducted.	Improved clinical integration and continuity of care across settings. Clear roles and responsibilities for all providers.

RECOMMENDATION 11: Ensure that palliative care education is available and accessible for all providers

Initiatives	Activities	Deliverables	Outcomes
Identify palliative care competencies required for each discipline, level of care provider (primary, secondary, tertiary) and type of care setting (LTCH, hospital, community).	Year one: Create an Education Task Group. In conjunction with provincial work, identify the required competencies for each type of provider and setting based on their roles & responsibilities. Conduct a gap analysis of current competencies in the North West.	Education Task Group is established. List of competencies for each type of care provider and setting is completed. A gap analysis is completed.	Consistent and standardized education and competencies for providers in all settings.
Identify the coaching and mentoring roles required to build and sustain palliative care competencies in the different levels of care.	Year one: Identify the number and type of coaches and mentors required and match against current resources.	Coaching/mentorship needs assessment is completed.	Increased access to palliative care education and training that addresses gaps in competencies.
Promote education and training opportunities across the region to assist providers in meeting the competencies.	Year two: Develop a plan to leverage existing coaches/mentors to deliver education & training to address the gaps in competencies. Work with educational institutes to incorporate palliative care education into the curriculum of future providers. Year two and beyond: Collaborate with partners to promote and deliver palliative care education & training using innovative approaches and evaluate these initiatives.	A regional palliative care education service plan is created. Partnerships with the education sector are established. A Community of Practice is created. Annual evaluation of education and training initiatives is conducted.	Increased number of providers that meet the competencies.

RECOMMENDATION 12: Support the use of innovative technologies to provide access to 1) consultation & support, and 2) education & training

Initiatives	Activities	Deliverables	Outcomes
Work with partners to identify and pilot innovative approaches for delivering palliative care consultation and education (e.g. through OTN, telehomecare, online learning, SIM labs).	<p>Year one: Form a Telemedicine Task Group to evaluate innovative projects using technology, explore opportunities for expansion, and plan and implement new projects.</p> <p>Year one and beyond: Ensure alignment and facilitate linkages between new and established telemedicine projects.</p>	A Task Group is established. Evaluations on existing projects are summarized and options for expansion are identified.	<p>Technology is used as an enabler to improve access to quality palliative care and palliative care education.</p> <p>Increased awareness amongst all providers regarding the use of telemedicine to deliver care and access education and training opportunities.</p>

RECOMMENDATION 13: Measure, monitor, and evaluate overall system performance

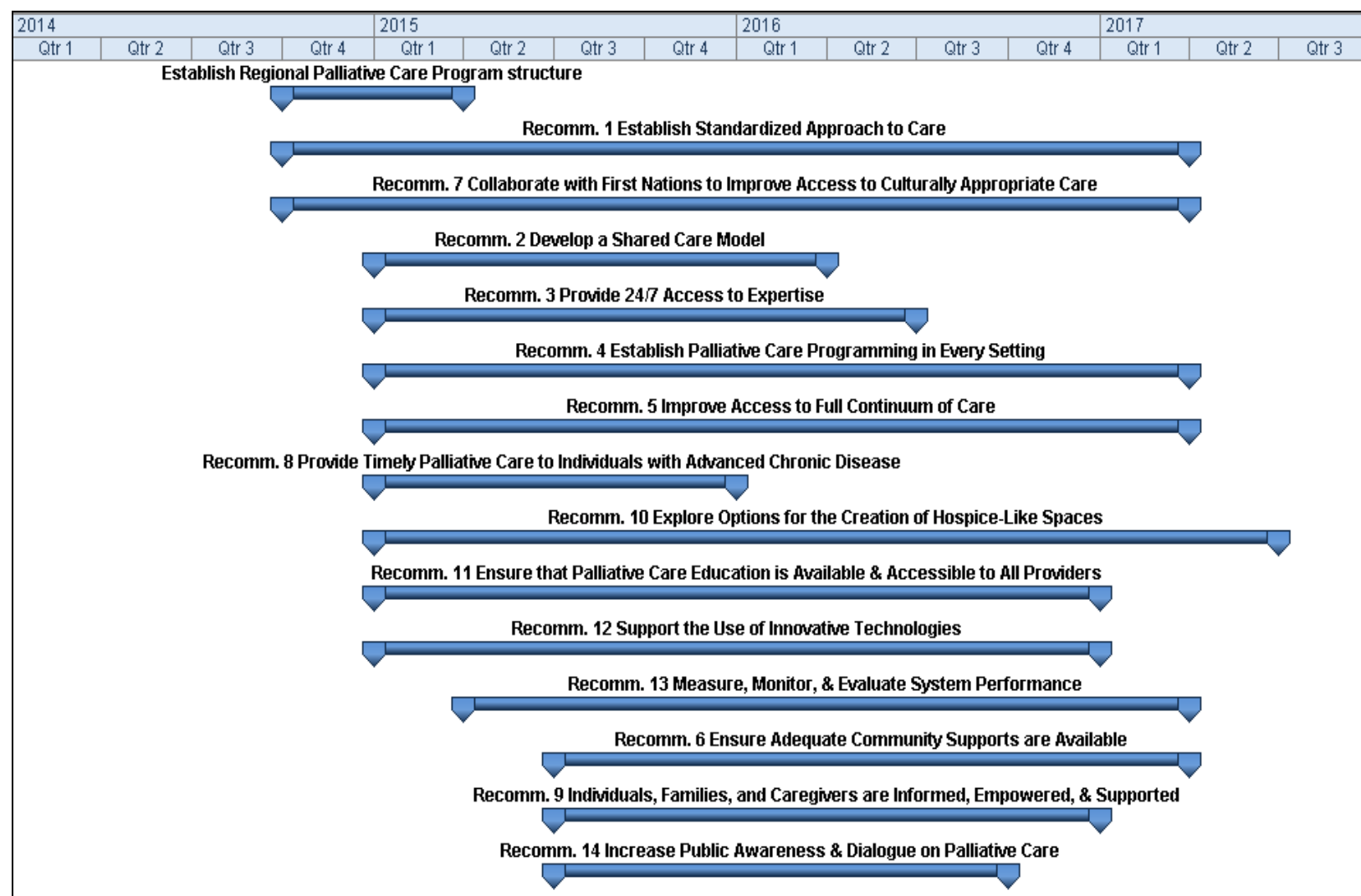
Initiatives	Activities	Deliverables	Outcomes
Use CQI methodology to strengthen the system and guide future work.	<p>Year one and beyond: Complete an annual evaluation of progress on the implementation plan. In conjunction with provincial work, develop indicators to measure quality of experience and client and caregiver satisfaction.</p> <p>Year two: Produce an annual report on the overall performance of the palliative care system for the North West LHIN.</p> <p>Year three: Conduct a focus group/VSM session with clients & caregivers to identify success of work to date and areas for improvement.</p>	<p>Annual progress report is completed.</p> <p>Indicators to measure client & caregiver experience and satisfaction are developed.</p> <p>Balanced scorecard is developed and completed annually.</p> <p>One QI session with clients & caregivers is conducted.</p>	<p>Strengthened accountability.</p> <p>Continuous quality improvement.</p> <p>Improved client and caregiver experience.</p> <p>Reduced # of hospital days attributed to palliative care.</p>

RECOMMENDATION 14: Increase public awareness and dialogue on palliative care

Initiatives	Activities	Deliverables	Outcomes
Work with Community Palliative Care Teams and HSPs to identify opportunities to start a dialogue on issues related to death & dying, building on provincial and national initiatives such as the Speak Up campaign and Compassionate Communities movement.	<p>Year one: Review existing public education and promotional materials.</p> <p>Year two and beyond: Disseminate materials to Community Palliative Care Teams and HSPs to promote Advance Care Planning Day and Hospice Palliative Care Week.</p> <p>Create a summary of public awareness activities.</p>	<p>Review of existing materials is completed.</p> <p>ACP materials are distributed to all hospitals, LTCHs, FHTs, and CCAC offices.</p> <p>A summary report is completed.</p>	<p>Increased awareness of the importance of advance care planning.</p> <p>Increased normalization and cultural acceptance of death & dying.</p> <p>Increased involvement of citizens and communities in supporting individuals who are dying and their families.</p>

The following Gantt chart illustrates the phased implementation of the recommendations described in this plan.

Figure 9: Gantt Chart for the Implementation Plan



6.0 List of Recommendations

The following recommendations will support the development of a comprehensive, coordinated system of palliative care in the North West LHIN. A Regional Palliative Care Program will be created to provide the leadership and oversight for the implementation of this plan.

1. Establish a standardized approach to care across settings and providers.
2. Develop a shared care model for palliative and end-of-life care whereby primary level providers deliver the majority of care with back-up support from secondary and tertiary level experts.
3. Provide 24/7 access to tertiary level expertise for providers across the North West LHIN.
4. Palliative care programming will be available in every health care setting.
5. Explore opportunities to improve access to a full continuum of care across the North West LHIN.
6. Ensure that adequate community supports are available across the North West LHIN to allow individuals to experience a good quality of life and death at home.
7. Collaborate with First Nations communities and organizations to improve access to culturally appropriate palliative care services and support for their members.
8. Provide quality, timely palliative and end-of-life care to individuals with advanced or progressive chronic diseases.
9. Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision.
10. Explore options for the creation of hospice-like spaces in key care settings where people die.
11. Ensure that palliative care education is available and accessible for all providers.
12. Support the use of innovative technologies to provide access to 1) consultation & support, and 2) education & training.
13. Measure, monitor, and evaluate overall system performance.
14. Increase public awareness and dialogue on palliative care.

7.0 Conclusion

The regional plan provides high level recommendations for advancing high quality palliative care across the North West LHIN over the next three years. Significant community and stakeholder engagement informed these recommendations and it is anticipated that many of the individuals and organizations who provided input will continue to be involved as implementation gets underway.

Currently, palliative care is provided to residents of the North West LHIN in multiple care settings by a variety of providers, including volunteers and informal caregivers. However, there are major gaps in communication and coordination across settings and providers, resulting in less than optimal experiences for clients and caregivers.

Implementation of the proposed recommendations will result in a regional system of palliative care that offers comprehensive support to all individuals and families who are coping with a life limiting illness or advanced chronic disease, regardless of where they live. Clients and caregivers will experience care that is responsive to their needs and seamless in its delivery. Primary care providers will be well supported by palliative care experts to deliver high quality palliative care to individuals and families in the community.



Overall, the North West LHIN is well positioned to advance the vision and priorities described in the Provincial Declaration. There are many opportunities for the North West LHIN to work in collaboration with the provincial HPC Steering Committee to leverage the public health approach to palliative care to develop capacity in rural, remote, and First Nations communities.

The passion and commitment demonstrated by providers across the region offers a strong foundation on which to build. The creation of a Regional Palliative Care Program will harness these strengths to create a system of palliative care that benefits all residents of the North West LHIN.

8.0 References

Brazil, K., Hampton, M., Hanson, G., Katt, M., Kelley, M.L., Minore, B., O'Brien, V., & Prince, H. (2012). *End of Life Perspectives and Experiences in Four First Nations Communities*. Poster presentation.

Canadian Hospice Palliative Care Association. (2002). *A Model to Guide Hospice Palliative Care*. Ottawa, ON.

Canadian Hospice Palliative Care Association. (2012). *The Palliative Approach: Improving Care for Canadians with Life-Limiting Illnesses*. Retrieved from www.hpcintegration.ca/resources/discussion-papers/palliative-approach-to-care.aspx

Canadian Hospice Palliative Care Association. (2013). *What Canadians Say: The Way Forward Survey Report*. Retrieved from www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf

Improving End-of-Life Care in First Nations Communities. Project website can be accessed at <http://www.eolfn.lakeheadu.ca/>.

Kelley, M.L., Williams, A., DeMiglio, L., & Mettam, H. (2011). *Developing Rural Palliative Care: Validating a Conceptual Model*. Journal of Rural & Remote Health. 11:1717.

Ministry of Health & Long-Term Care. (2011). *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership & Commitment to Action*. Toronto, ON.

Ministry of Health & Long-Term Care. (2013). *Palliative Care in Ontario: January 2013 update*. Toronto, ON.

North West Local Health Integration Network. (2013). *Population Health Profile*. Thunder Bay, ON.

Ontario Association of Community Care Access Centres (OACCAC), Ontario Federation of Community Mental Health and Addiction Programs (OFCMHAP) & The Ontario Hospital Association (OHA). (2010). *Ideas and Opportunities for Bending the Health Care Cost Curve. Advice for the Government of Ontario*. Toronto, ON.

Preyra Solutions Group. (2012). *Expected Number of Deaths in the North West LHIN*.

Quality Palliative Care in Long-Term Care: A Community-University Research Alliance. Project website can be accessed at www.palliativealliance.ca.

Vital Statistics. (2013). Death Data Table, IntelliHEALTH ONTARIO.

Appendices

Appendix A – Alignment with Provincial & North West LHIN Priorities

Regional Palliative Care Plan Recommendations	MOHLTC Pillars			
	Home & Community	Integration	Healthier Ontario	Quality & System Funding
Establish a standardized approach to care across settings and providers.		X		
Develop a shared care model for palliative and end-of-life care.	X	X		
Provide 24/7 access to tertiary level expertise for providers across the North West LHIN.		X		
Palliative care programming will be available in every health care setting.	X	X		
Explore opportunities to improve access to a full continuum of care across the North West LHIN.		X		
Ensure that adequate community supports are available across the North West LHIN.	X			
Collaborate with First Nations communities and organizations to improve access to culturally appropriate palliative care services and support.	X	X		
Provide quality, timely palliative and end-of-life care to individuals with advanced or progressive chronic diseases.	X	X		
Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision.	X		X	
Explore options for the creation of hospice-like spaces in key care settings where people die.		X		
Ensure that palliative care education is available and accessible for all providers.				X
Support the use of innovative technologies to provide access to 1) consultation & support, and 2) education & training.	X			
Measure, monitor, and evaluate overall system performance.				X
Increase public awareness and dialogue on palliative care.			X	

Regional Palliative Care Plan Recommendations	North West LHIN Strategic Directions			
	Population Health	Access	Continuous Quality Improvement	Culture of Accountability
Establish a standardized approach to care across settings and providers.		X	X	X
Develop a shared care model for palliative and end-of-life care.		X		
Provide 24/7 access to tertiary level expertise for providers across the North West LHIN.		X		
Palliative care programming will be available in every health care setting.		X	X	X
Explore opportunities to improve access to a full continuum of care across the North West LHIN.		X		
Ensure that adequate community supports are available across the North West LHIN.		X		
Collaborate with First Nations communities and organizations to improve access to culturally appropriate palliative care services & support.		X		
Provide quality, timely palliative and end-of-life care to individuals with advanced or progressive chronic diseases.		X		
Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision.		X	X	
Explore options for the creation of hospice-like spaces in key care settings where people die.		X		
Ensure that palliative care education is available and accessible for all providers.		X	X	X
Support the use of innovative technologies to provide access to 1) consultation & support, and 2) education & training.		X	X	
Measure, monitor, and evaluate overall system performance.			X	X
Increase public awareness and dialogue on palliative care.	X			

Regional Palliative Care Plan Recommendations	Provincial Declaration Priority Areas					
	Access	Caregiver Supports	Service Capacity & Human Capital	Integration & Continuity of Care	Accountability	Public Awareness
Establish a standardized approach to care across settings and providers.	X			X	X	
Develop a shared care model for palliative and end-of-life care.	X		X	X		
Provide 24/7 access to tertiary level expertise for providers across the North West LHIN.	X		X			
Palliative care programming will be available in every health care setting.	X			X	X	
Explore opportunities to improve access to a full continuum of care.	X	X		X		
Ensure that adequate community supports are available across the North West LHIN.	X	X				
Collaborate with First Nations communities and organizations to improve access to culturally appropriate palliative care services & support.	X		X	X		
Provide quality, timely palliative and end-of-life care to individuals with advanced or progressive chronic diseases.	X			X		
Individuals, families, and caregivers are informed, empowered, and supported to participate in care planning and provision.		X				
Explore options for the creation of hospice-like spaces in key care settings where people die.	X			X		
Ensure that palliative care education is available and accessible for all providers.			X	X		
Support the use of innovative technologies to provide access to 1) consultation & support, and 2) education & training.	X	X	X	X		
Measure, monitor, and evaluate overall system performance.					X	
Increase public awareness & dialogue on palliative care.						X

Appendix B – Community Engagement Summary

The following is a summary of key community engagement activities that supported the development of this plan.

Community Visits

In order to assess the current state of palliative care in Northwestern Ontario and to gain insight into priorities for the Regional Plan for Palliative Care, the End-of-Life Care Network Lead travelled to 8 communities to talk to stakeholders in the Fall of 2013.

A 1.5-2.0 hour meeting was held in each community. These meetings were open to anyone with an interest in palliative & end-of-life care. The majority of participants were frontline care providers, including physicians, nurses, social workers, case managers, hospice volunteers, and personal support workers. There was also representation from the management and administration levels of various organizations, as well as participants from community support agencies and First Nations communities. Table 1 below summarizes the number of participants by community and the care setting in which they work.

Table 1 – Summary of Participants

Community Meeting Locations	Total # of Participants	Primary Care (MDs, NPs, FHT)	Home Care (CCAC, PSWs)	Hospital (mgmt, OT/PT)	Long-Term Care	Hospice Volunteer	Community Support Agencies	First Nations Comms /Orgs
Manitouwadge	5	3	1	1	0	0	0	
Geraldton	21	5	0	4	0	11	0	1
Kenora	14	1	0	6 + 3 students	0	1	1	2
Red Lake	8	3	1	2	0	1	1	0
Sioux Lookout	23	1	2	8	0	0	6	6
Dryden	15	1	1	5		3	1	4
Fort Frances	5	0	0	3	0	0	1	1
Atikokan	4	0	2	0	0	0	2	0
TOTAL	95	14	7	32	0	16	12	14

Furthermore, the following communities were represented by individuals who attended the meetings:

Longlac

Pickle Lake

Mishkeegogamang First Nation

Lac Seul First Nation

Eagle Lake First Nation

Emo

In the community meetings, participants were given an overview of the provincial Declaration of Partnership & Commitment to Action and the priorities that had been identified therein. They were then asked to describe the current state of palliative care in their community, thinking of different components of quality palliative care (human resources, equipment, medication,

programs & services) as well as the different care settings available (home/community, long-term care, acute care).

In order to identify priorities for the regional plan, an “ideal” state was presented and participants were asked to identify the gaps between the current state and ideal state. They were also asked to identify what changes to the system would have the greatest impact on improving care for individuals & families in their community. A discussion was then held about how a Regional Palliative Care Program could support them in providing better palliative care in their community.

Online Survey

To provide an additional opportunity for interested stakeholders to offer input into the Regional Plan, an online survey was created through Survey Monkey. The survey link was circulated to members of the EOL Care Network and they were encouraged to share it with anyone else who might be interested. Fifty-nine (59) people completed the survey between November and December 2013, representing a variety of roles, settings, and communities.

The survey questions were open-ended and asked respondents to describe what was working well, what needs improvement, and where things go wrong and why. The survey also asked about the greatest barriers to providing high quality palliative and end-of-life care in their community and how a Regional Palliative Care Program could provide support to enhance the delivery of high quality care.

Value Stream Mapping & Quality Improvement Session

In March 2014, a palliative care value stream mapping and quality improvement session took place over two days in Thunder Bay. The session was co-facilitated by Health Quality Ontario and the NWO EOL Care Network. The focus was on engaging caregivers, volunteers, and frontline workers to discuss the current state of the system from the individual client and family’s perspective and describe a vision for the future.

A total of 26 individuals attended the session, representing 4 of the 5 IDNs. Sixteen (16) were from the City of Thunder Bay while ten (10) travelled in from communities across the region. These communities included Marathon, Terrace Bay, Geraldton, Longlac, Fort Frances, and Kenora.

The following organizations & sectors were represented:

Caregivers & hospice volunteers – 9
St. Joseph’s Care Group - 2
Thunder Bay Regional Health Sciences Centre – 2
NW CCAC – 3
Long-Term Care Homes – 3
Acute Care (region) – 2
Home & Community Care - 1
First Nations service providers - 2
Nursing Students - 2

Appendix C - Prevalence of Chronic Conditions in the North West LHIN

Indicator		North West LHIN	ON
Canadian Community Health Survey (CCHS) 2011-2012: % report being diagnosed by health professional ¹			
Arthritis	-age 15+	21.5%**	17.2%
	-age 65+	50.2%	44.4%
Diabetes	-age 12+	7.6%	6.6%
	-age 65+	13.8%** ▼	18.6%
High blood pressure	-age 12+	21.1%**	17.6%
	-age 65+	56.3%**	49.3%
Chronic obstructive pulmonary disease (COPD), age 65+		8.0%	7.3%
Hospitalization rates, fiscal year 2011-2012: crude rate/100,000 population ²			
Arthritis		524.5**	343.3
Diabetes		208.8**	95.8
Chronic obstructive pulmonary disease (COPD)		367.7**	181.0
Congestive heart failure (CHF)		275.1**	157.5
Ischemic heart disease (IHD)		566.5**	360.6
Stroke		210.5**	129.1

** Statistically different from the provincial rate

▼ Significantly lower than previous period (2009/2010)

Sources: 1. Statistics Canada, CCHS. CANSIM Table 105-0502, accessed Nov. 2013

2. HAB, MOHLTC, NW Health Links Profile revised, Nov. 2013

Appendix D – Current Palliative Care Programming by Hospital

Service	City of Thunder Bay IDN		District of Thunder Bay IDN					District of Kenora IDN			District of Rainy River IDN				Northern IDN
	TBRHS C	St. Joseph's Hospital	Geraldton District Hospital	Manitou-wadage General Hospital	Wilson Memorial General Hospital	Nipigon District Memorial Hospital	McCausland Hospital	Lake of the Woods District Hospital	Margaret Cochenour Memorial Hospital	Dryden Regional Health Centre	Rainy River Health Centre	Emo Health Centre	La Verendrye General Hospital	Atikokan General Hospital	Meno Ya Win Health Centre
Mandatory staff education on palliative care															
In-house palliative care resource team	X	X				X		X						X	
Self-designated palliative care room(s)/bed(s)		X	X	X	X	X	X			X			X	X	X
Access to palliative care expertise 24/7	X	X	X							X					
Advance Directives / Advance Care Planning discussion upon admission	X	X	X			X	X		X	X				X	X
Formal identification & assessment of clients who would benefit from a palliative approach to care		X	X							X					
Information available to family/caregivers on palliative and end-of-life care	X	X	X		X	X	X	X	X	X	X	X	X	X	
Community partnerships to support palliative care delivery	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Service	City of Thunder Bay IDN		District of Thunder Bay IDN					District of Kenora IDN			District of Rainy River IDN				Northern IDN
	TBRHS C	St. Joseph's Hospital	Geraldton District Hospital	Manitowadge General Hospital	Wilson Memorial General Hospital	Nipigon District Memorial Hospital	McCausland Hospital	Lake of the Woods District Hospital	Margaret Cochenour Memorial Hospital	Dryden Regional Health Centre	Rainy River Health Centre	Emo Health Centre	La Verendrye General Hospital	Atikokan General Hospital	Meno Ya Win Health Centre
Grief & bereavement protocols to support families and staff following a death		X						X							

Appendix E – Current Palliative Care Programming by Long-Term Care Homes

Service	City of Thunder Bay IDN								District of Thunder Bay IDN	District of Kenora IDN				District of Rainy River IDN	Northern IDN
	Betham i	Hogarth Rivervie w Manor	Grandvie w Lodge	Dawso n Court	Pione r Ridge	Lakehea d Manor	Pinewoo d Court	Rosevie w Manor	Wilkes Terrace	Pinecres t	Birchwoo d Terrace	Princes s Court	Northwoo d Lodge	Rainycres t	William A. George Extended Care Facility
Mandatory staff education on palliative care			X		N/A			N/A	X		N/A	N/A		X	
In-house palliative care resource team	X	X	X	X		X	X								
Self-designated palliative care room(s)/bed(s)			X							X				X	X
Access to palliative care expertise 24/7			X			X	X								
Advance Directives / Advance Care Planning discussion upon admission	X	X	X			X	X		X	X				X	X
Formal identification & assessment of clients who would benefit from a palliative approach to care			X			X	X								
Information available to family/caregivers on palliative and end-of-life care	X	X	X	X		X	X		X	X			X	X	
Community partnerships to support palliative care delivery	X	X	X	X	↓	X	X	↓	X	X	↓	↓	X	X	X

Service	City of Thunder Bay IDN								District of Thunder Bay IDN	District of Kenora IDN				District of Rainy River IDN	Northern IDN
	Bethammi	Hogarth Riverview Manor	Grandview Lodge	Dawson Court	Pioneer Ridge	Lakehead Manor	Pinewood Court	Roseview Manor	Wilkes Terrace	Pinecrest	Birchwood Terrace	Princess Court	Northwood Lodge	Rainycrescent	William A. George Extended Care Facility
Grief & bereavement protocols to support families and staff following a death	X	X			N/A	X	X	N/A		X	N/A	N/A	X	X	

N/A = Information on this Home's palliative care services not available at the writing of this report.

Appendix F – Community Support Services by Local Health Hub & IDN

Service*	City of Thunder Bay IDN	District of Thunder Bay IDN					District of Kenora IDN			District of Rainy River IDN				Northern IDN
	City of Thunder Bay	Green-stone	Manitou-wadge	Marathon	Nipigon	Terrace Bay	Kenora	Red Lake	Dryden	Rainy River	Emo	Fort Frances	Atikokan	Sioux Lookout
Caregiver Support	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Case Management	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Comb. PS/HM/Respite Services	X	X		X	X									
Community Health Promotion & Education - Palliative Care							X	X	X					
Day Services	X						X	X	X	X	X	X	X	
Home Maintenance	X	X	X		X	X	X	X	X			X		X
Homemaking	X	X					X	X	X	X	X	X	X	X
In-Home Health Care - Nursing - Visiting	X	X		X	X									
In-Home Health Care - Occupational Therapy	X	X		X	X									
In-Home Health Care - Physiotherapy	X	X		X	X									
In-Home Health Care - Social Work	X	X		X	X									
Meals Delivery	X			X		X	X	X	X	X	X	X	X	X
Respite	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Service*	City of Thunder Bay IDN	District of Thunder Bay IDN					District of Kenora IDN			District of Rainy River IDN				Northern IDN
	City of Thunder Bay	Green-stone	Manitou-wadge	Marathon	Nipigon	Terrace Bay	Kenora	Red Lake	Dryden	Rainy River	Emo	Fort Frances	Atikokan	Sioux Lookout
Transportation - Client	X	X		X			X	X	X	X	X	X	X	X
Visiting - Hospice Services	X	X		X	X	X	X	X	X			X	X	
Visiting - Social and Safety	X	X	X		X	X	X		X	X	X	X	X	X

*Functional centres by LHIN funded HSPs

Appendix G – Current Palliative Care Programs and Services in the North West LHIN

Program/ Service	Lead Agency	Description of Services	Clients Served (Criteria)	Service Stats
St. Joseph's Hospital - Hospice Palliative Care Unit (HPCU)	St. Joseph's Care Group	<ul style="list-style-type: none"> 32-bed unit comprised of 10 private rooms, one 2-bed semi-private room, and five 4-bed ward rooms. HPCU beds are CCC beds funded through SJCG's global budget. Tertiary level palliative care is provided for clients who have complex pain and symptom management needs (with a goal to return home) or who require end-of-life care. Care is provided by an interdisciplinary team including OT, PT, Dietitian, Rehabilitation Assistants, Spiritual Care Associate, Social Worker, Pharmacist, Nurses, and Palliative Care MDs. 	<p>Individuals with a prognosis of < 3 months <u>and/or</u> individuals with complex pain & symptom needs.</p> <p>Average Palliative Performance Scale (PPS) score on admission is 20-30%.</p> <p>80-85% have a cancer diagnosis and 15-20% have a chronic disease diagnosis.</p> <p>Only 1-2 clients/year are admitted from outside of the City of Thunder Bay IDN.</p>	<p>In 2012 there were 184 admissions and 170 deaths on the HPCU.</p> <p>70% of admissions come from acute care (TBRHSC).</p> <p>Average length of stay: Cancer – 7-13 days. Chronic disease – 60 days.</p> <p>75% of clients die within one month of admission. Less than 1% of clients return to community living</p>
CCAC End-of-Life Program	North West CCAC	<ul style="list-style-type: none"> Case management, care planning, nursing, personal support, homemaking, physiotherapy, occupational therapy, speech and language therapy, social work, and nutrition/dietetic services. Provides the individual and family with the appropriate medical equipment and 	Individuals with a prognosis of 6 months or less, and a PPS score of 50% or less.	In 2011/12, the NW CCAC provided services to 375 clients with an EOL service goal in the North West LHIN region.

Program/ Service	Lead Agency	Description of Services	Clients Served (Criteria)	Service Stats
		<p>supplies so that care can be provided in their home.</p> <ul style="list-style-type: none"> ▪ Referral to other services. ▪ Bereavement visit with family following death. 		Approximately 4% of all CCAC services are provided to those with an End-of-Life service goal.
Palliative Pain & Symptom Management Consultant Program (PPSMCP)	North West CCAC	<ul style="list-style-type: none"> ▪ 1.0 FTE Nurse Practitioner provides consultation, education, linkages, and mentorship to build the capacity of frontline care providers. ▪ The program provides access to palliative pain & symptom management expertise. ▪ The program does not provide direct client assessment or care planning but is focused on mentoring and coaching the service providers who do. ▪ Consultation can be offered in person, by telephone, by videoconference (OTN) or through e-mail. 	Service providers working in home care, long-term care, primary care, and community support services (e.g. Group Homes, Assisted Living, & supportive housing).	In 2013 the PPSMCP provided 359 group sessions and 353 individual sessions, reaching just over 4,000 participants.
Palliative Care Nurse Practitioners (PC NPs)	North West CCAC	<p>5.0 FTE NPs to:</p> <ul style="list-style-type: none"> ▪ assess clients' palliative care needs ▪ provide direct clinical care in the home; ▪ identify the preferred and most appropriate location for care as the individual's disease progresses; ▪ mentor, support, and educate other members of the individual's health care team to provide quality, holistic, client centred care; ▪ improve pain and symptom management; ▪ make referrals to specialist services as necessary. <p>One NP to be hired per IDN.</p>		<p>The PC NP program was initiated in 2012/13 across the province.</p> <p>In the North West LHIN, NPs have been hired in the City of Thunder Bay, District of Thunder Bay, and Rainy River IDNs.</p>

Program/ Service	Lead Agency	Description of Services	Clients Served (Criteria)	Service Stats
Hospice Volunteers	Hospice Northwest (City of Thunder Bay & District of Thunder Bay IDNs)	<ul style="list-style-type: none"> One-on-one support and companionship. Can include friendly visiting; assistance with shopping, laundry, & meal preparation; transportation; and advocacy. Grief and bereavement support. 	<p>Individuals living with a life-threatening illness or disease with prognosis of < one year.</p> <p>Individuals who have experienced the death of a loved one.</p>	<p>Hospice Northwest:</p> <ul style="list-style-type: none"> 250 trained volunteers 350 individuals & families served per year
	Kenora Home for the Aged (Kenora and Rainy River IDNs)	<ul style="list-style-type: none"> Services can be provided in the client's private home, in the hospital, or in a long-term care setting. All services are provided at no cost to the client. Base funding from the North West LHIN is supplemented by fundraising, private donations, and the United Way. 		<p>Kenora-Rainy River District Palliative Care Volunteer Program:</p> <ul style="list-style-type: none"> 100 trained volunteers 130 individuals & families served per year
	No hospice volunteer program in the Northern IDN.			
Telemedicine Nurse – Palliative Care	St. Joseph's Care Group	<ul style="list-style-type: none"> 1.0 FTE Telemedicine Nurse provides assessment, education and support to clients, families, caregivers and peers (nursing and allied health) on a client specific basis for the North West LHIN region. Services are provided virtually through the Ontario Telemedicine Network (OTN). Linkages with First Nations' Home & Community Care Programs for peer consultation and support. 	<p>Individuals who are dealing with a life limiting illness that affects their quality of life, their families, & caregivers.</p> <p>Referrals are accepted from client, family members, & other health care professionals.</p>	<p>The Telemedicine Nurse has provided support to clients and families living in communities such as Fort Severn, Deer Lake, Poplar Hill, Sandy Lake, Dryden and the City of Thunder Bay.</p>
Regional Cancer Program –	Regional Cancer Care	<ul style="list-style-type: none"> 0.8 FTE Palliative Care Clinician (RN) provides consultation and support to any 		

Program/ Service	Lead Agency	Description of Services	Clients Served (Criteria)	Service Stats
Supportive Care	Northwest/ TBRHSC	<p>individual and family admitted to TBRHSC. PC Clinician works out of TBRHSC but is employed by SJCG.</p> <ul style="list-style-type: none"> 1.0 FTE Palliative Care Physician Lead for Regional Cancer Care. 1.0 FTE RN runs a Pain & Symptom Management Clinic. The Supportive Care team provides social work, counseling, spiritual care, and nutrition services to cancer patients and their families. First Nations Patient Navigator. Televisitation. 		
Interdisciplinary Palliative Care Education	Centre for Education & Research on Aging and Health (CERAH) at Lakehead University	<ul style="list-style-type: none"> Palliative care education courses including Learning Essential Approaches to Palliative & End-of-Life Care (LEAP), Palliative Care for Front Line Workers and Palliative Care for Front Line Workers in First Nation Communities. Collaborates with the Northern Ontario School of Medicine (NOSM) to deliver regular presentations over OTN called the Palliative Care Education Series. Partners with other organizations to deliver simulation-based education sessions, hospice volunteer education, and workshops on various topics (i.e. Grief & Communication). Organizes an annual palliative care conference that attracts providers from across the region. 	Service providers including physicians, nurses, social workers, pharmacists, OT, PT, personal support workers, health care aides, pastoral care workers and hospice volunteers, with a particular focus on providers in the community and long-term care sectors.	In 2012/13, CERAH delivered 106 education sessions representing a total number of 280 hours of education, attended by 4,251 participants (including 104 physicians).

