An Evaluation of

Naotkamegwanning First Nation's

Wiisokotaatiwin Pilot Program

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The evaluation team consisted of Dr. Shevaun Nadin, Evaluation Specialist; Dr. Mary Lou Kelley, Principal Investigator; Holly Prince, Co-investigator and Project Manager and Maxine Crow, Community Facilitator and Naotkamegwanning Community Care Coordinator. The evaluation team would like to thank the Canadian Institutes of Health Research (CIHR) for their financial contribution and support of the EOLFN research project. We would also like to thank the North West Local Health Integration Network (NW LHIN) for their financial support to pilot test and evaluate the Wiisokotaatiwin Program.

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EXECUTIVE SUMMARY

BACKGROUND

The need to develop culturally appropriate palliative care programs in First Nations communities is urgent because the First Nations population is aging with a high burden of chronic and terminal disease. Though First Nations people want the opportunity to die at home in their communities, because of a lack of formalized palliative care services in First Nations communities, many die in urban areas separated from family, community and culture.

This evaluation took place within the context of the *Improving End-of-Life Care in First Nations Communities (EOLFN)* research project. Using a participatory action research approach, the EOLFN research team partnered with four First Nations communities to develop local palliative care programs within each community. Naotkamegwanning First Nation was one of those communities. Details of the community capacity development methodology can be found on the project website in the Developing Palliative Care in First Nations Community: A Workbook (see www.eolfn.lakeheadu.ca). While the EOLFN project funded community capacity development, it was unable to fund health services.

After three years of community capacity development, Naotkamegwanning developed a local program designed to care for people who were very sick in their community. This program was embedded in and influenced by their local cultural protocols, values and beliefs. Within the community of Naotkamegwanning, talking about death and dying is not culturally appropriate and there are many teachings in the community about this. Therefore, the use of certain words had to be avoided. In addition, palliative care is a westernized concept and there is no word for it in the Anishinaabe language. The Naotkamegwanning Leadership Team took the direction from their Elders and called their program “The Wiisokotaatiwin Program” which translates to "taking care of each other or supporting each other."

Through the enhancement and integration of existing services, Wiisokotaatiwin sought to provide people living in Naotkamegwanning the option to receive care at home by allowing for services and supports to be available 24 hours a day, 7 days a week in Naotkamegwanning. With funding from the North West Local Health Integration Network (NW LHIN) for enhanced resources and service delivery within the community, the program was piloted for 10 months (November 2014 – August 2015). Throughout the pilot, the EOLFN project team supported the community capacity development and completed this evaluation of “The Wiisokotaatiwin Program.”

EVALUATION

This process evaluation sought:

- To document program implementation:
  - What resources were required to implement the pilot?
  - Were the 'essential program activities' implemented in the pilot?
  - Who participated in the program (# and profile of clients)?
  - What services were provided to clients (by who, when, and where)?
- To report on the accountability / success indicators that were specified in the funding proposal.
- To assess the value of the Wiisokotaatiwin Program.

METHODS

A variety of quantitative and qualitative data were collected via Weekly Client Tracking Forms (May – August 2015), Questionnaires, Focus Group/Interviews, and various Program Documents.

RESULTS

Program Implementation

All of the required resources were in place (i.e., local palliative care service providers, regional health services, funds, facilitation/support from EOLFN project). In addition, all of the 'essential program activities' were implemented (i.e., education of community and health care professionals (HCPs), coordination of local palliative care services, partnerships/service agreements with regional health services, development of program guidelines).

There were six clients on the program during the pilot period. All were elderly and living with a chronic illness. A palliative care case conference was held in the community for each client, and an integrated care plan was developed and implemented. During the weekly tracking sample period (May – August 2015), clients received an average of 51 hours of direct client services a month; many of which were delivered on evenings and weekends.

In general, the care plans involved two nursing visits a week (different days) and several hours of home support provided by personal support workers (PSW), homemakers and home support workers. Intensive case management was also provided to each client. There was evidence that three unnecessary Emergency Department (ED) visits and one hospital admission were avoided because of these services during the weekly tracking sample period.

Program Value

Clients, families, and health care providers were satisfied with the program; they thought it was a worthwhile project that was meeting its objectives. However, there was a concern that the program was not sustainable without continued service delivery funding, and there was an expressed need for ongoing palliative care funding. For example, some participants stated:

"This was a good program to start the conversation of support for sick and elderly in their home ...I feel the program gave the community confidence to move forward." (Internal Health Care Provider)

"I think for me, one of the major positive things that happened was creating those partnerships and starting that communication with our health care providers." (Leadership Team Member)

"The Wiisokotaatiwin Program is an excellent example of community driven palliative care service coordination. They have overcome barriers to services delivery by thinking outside of the box, looking within to existing community services and reaching our where needed to establish necessary linkages. All this was done at very little cost to the health care system – although it should be acknowledged that the people involved at the community level have worked exceedingly hard to make the program the success it is today." (External Health Care Provider)

"The pilot project created a fantastic program and many from the community were able to benefit from it. It is a program that can be transferred to other communities. The amount of extra funding needed to sustain the program was minimal and saved the healthcare system money in the long run. Need one of the governments to commit to ongoing palliative care funding." (External Health Care Provider)

SUMMARY OF EVALUATION FINDINGS & IMPLICATIONS

This evaluation demonstrated that the pilot program was implemented as intended, that there was a need for the program in Naotkamegwanning, and that progress was made toward the program's intended outcomes. The findings of the pilot project illustrate that the Naotkamegwanning community had both the motivation and capacity to care for their very sick community members at home. The LHIN funding provided them the needed opportunity, as did support from the EOLFN project team at Lakehead University.

Key to the success of the pilot were the capacity development work with the EOLFN project, and the dedication of the community and its health care providers. In addition, the service delivery funds from the NW LHIN were instrumental because that funding allowed for the enhancement and integration of services so that palliative care services and supports were available 24/7 in Naotkamegwanning during the pilot period. However, that level of service could not be sustained once the pilot funding ended.

As a case study, this pilot project suggests that other First Nations communities with similar motivation, capacity and opportunity could implement a local palliative care program, tailoring their program to their unique community needs, local resources and regional context.

1. INTRODUCTION

1.1. BACKGROUND

1.1.1. Palliative Care

Palliative care is an approach to health care aimed at preventing and relieving suffering, and improving the quality of life for people living with advanced illness and their families.[1] Although historically viewed as care provided to people in a hospice setting at the end of life, palliative care is also of benefit for people living with progressive chronic and terminal illnesses, including frailty.[2,3] Indeed, a palliative approach to care can be incorporated across the illness trajectory, integrated with treatment and chronic disease management (See Figure 1).[3,4]

Figure 1 below illustrates that therapy to treat disease is offered concurrently with the palliative approach to care from the time of diagnosis. Over time, the goals of care transition to a greater emphasis on palliative care and less emphasis on treatment of the disease. In particular, people in the last year of life who have a progressive chronic or terminal disease benefit from palliative care. End of life care focuses on the last days or weeks of life when the person is imminently dying. Early access to palliative care and advanced care planning have shown to contribute to increased client and family satisfaction with their end of life care experience and also improves the likelihood that people will die in the setting of their choice.[5,6] Grief support for patients, families and their emotionally involved community members is an important component of palliative care.

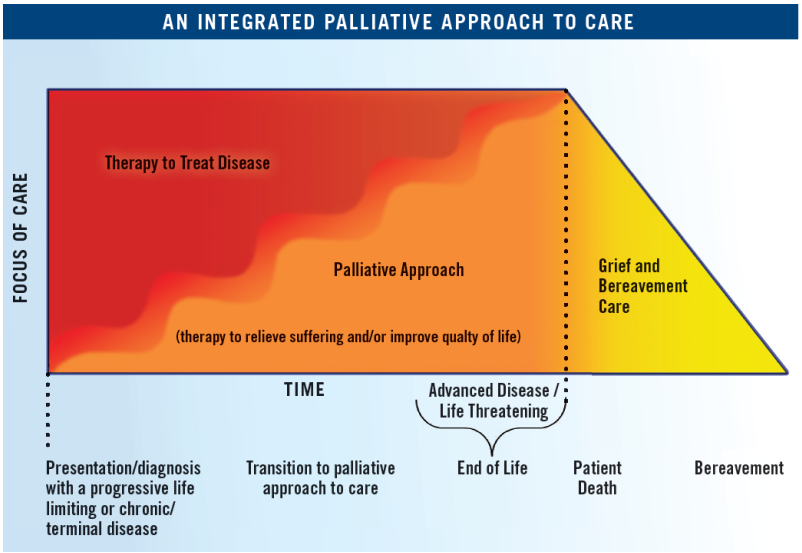

Figure 1. An Integrated Approach to Palliative Care. This figure illustrates how a palliative approach to care can be incorporated at different stages of a person's chronic illness.[3]

1.1.2. Palliative Care in First Nations Communities

The need to develop culturally appropriate palliative care programs in First Nations communities is urgent because the First Nations population is aging with a high burden of chronic and terminal disease.[7,8] First Nations people who are living with advanced, chronic and terminal illness want the opportunity to die at home in their communities.[3] However, First Nations communities currently lack the health services and other supportive community resources to meet the home care needs of people with complex and high intensity care needs. Thus, many people who live in First Nations communities die in regional or urban areas (in hospital or long-term care) separated from family, community and culture.

1.1.3. The Improving End-of-Life Care in First Nations Communities (EOLFN) Project

The EOLFN research project sought to address the need for formalized palliative care services in First Nations communities. Based at the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University, the project was conducted in partnership with four First Nations communities. It was a participatory action research project funded by the Canadian Institutes of Health Research (2010-2015). Using a community capacity development approach, the goal was to improve the end-of-life care in each of the partner communities by developing a community-based palliative care program and team in each community. [3,9] Naotkamegwanning First Nation was one of those communities.

1.1.4. Naotkamegwanning First Nation

Naotkamegwanning First Nation is located in North Western Ontario in the Treaty #3 Territory. The nearest urban center Kenora (approx. 15,000 people) is 96 km north of the community. The community has year-round road access including an ice road in winter. There are 712 community members living in the community. Naotkamegwanning is one of the very few communities that have been able to keep their Anishinaabe cultural practices and beliefs strong and vibrant with approximately 48% of the population able to speak Ojibway. Many of the people of Naotkamegwanning continue a connection with the land and maintain a lifestyle that includes fishing, hunting and harvesting wild rice. The importance of passing on teachings, language and cultural practices are evident in their delivery of programs and services within the community. The community cultural context strongly influences the way death and dying is viewed and discussed in the community

In 2007, Naotkamegwanning integrated the First Nations and Inuit Health Branch's Home and Community Care program which provides basic home care services such as nursing, personal support and respite with the provincially funded Long-Term Care Program which provides home support and home maintenance. This integrated model of care, called Naotkamegwanning's Community Care Program, provides a single point of access with customized care plans for those requiring service.

For over three years, Naotkamegwanning worked with the EOLFN research team to guide the community development process, build palliative care capacity, and develop a local palliative care program. This included hiring an individual from Naotkamegwanning as a community facilitator to lead local implementation of the project, conducting a local palliative care needs assessment and establishing a palliative care Leadership Team[3]. The Leadership Team was responsible for the development, implementation and evaluation of their local palliative care program. The team was comprised of local leadership, health care providers, Elders and community members, along with a community facilitator and a project resource/liaison person, a retired nurse, both of whom were paid by the EOLFN project. A series of 'Journey Mapping' workshops were also held to map out the current and desired state of palliative care service provision in Naotkamegwanning.

The Journey Mapping workshops identified gaps in service, and needed service enhancements. Specifically, the First Nations and Inuit Health Branch Home and Community Care Program (HCCP) which has been designed to provide basic home and community care services to First Nations communities does not fund palliative care as a unique program. However, the essential services required to provide palliative home care are funded and in place (i.e. case management, nursing, personal care).

There are no FNIHB home care services funded on evenings or weekends (HCCP hours were Monday – Friday, 8:30 a.m. – 4:30 p.m.). Thus, people with advanced chronic or terminal illness often accessed palliative care services and supports outside of the community, and all people living in Naotkamegwanning who were dying from progressive chronic or terminal illnesses died in hospital. The workshops also identified key partners that could facilitate the coordination and integration of services that clients need as they access various services and health care providers.

The three years of capacity building and the Journey Mapping Workshops resulted in the creation of Naotkamegwanning First Nation's palliative care program model – The Wiisokotaatiwin program. However, the community was unable to deliver the program due to a lack of service delivery funds. Thus, Naotkamegwanning First Nation applied to the North West LHIN for pilot project funding for the Wiisokotaatiwin program. The application was completed using the required LHIN Health Services Improvement Pre-Proposal form (HSIP) (See Appendix A). The program was funded for 10 months (November 2014 – August 2015).

1.2. THE WIISOKOTAATIWIN PROGRAM

1.2.1. Vision & Aims

The Wiisokotaatiwin Program aimed to provide coordinated, comprehensive, person-centered care to persons who are very sick and who wish to return home to Journey.[10] The vision was to "have available for Naotkamegwanning First Nation members, coordinated comprehensive services for those wishing to return home to Journey, maintaining use of individual traditions and spiritual beliefs."[10]

1.2.2. Eligible Clients

A referral to the program was appropriate if the client:
a) Could benefit from the services of the program, and
b) Wished to receive their care at home, and
c) Had an illness from which no recovery is expected, and
d) Had a Palliative Performance Scale (PPS) score of ≥ 60% with a prognosis of declining to 0% within 1 year.

1.2.3. Program Description

Wiisokotaatiwin adopted a service integration and enhancement model to address the need for palliative care services and support to be available 24 hours a day, 7 days a week in Naotkamegwanning.

A program logic model depicts the resources, essential activities, and intended outcomes of the Wiisokotaatiwin Program (See Figure 2). Figure 3 illustrates the Wiisokotaatiwin Care Pathway. Box 1 outlines the services and service providers involved in the Wiisokotaatiwin Care Pathway.

Figure 3. Wiisokotaatiwin Care Pathway.[10] This Figure Illustrates the expected care for clients on the Wiisokotaatiwin program.

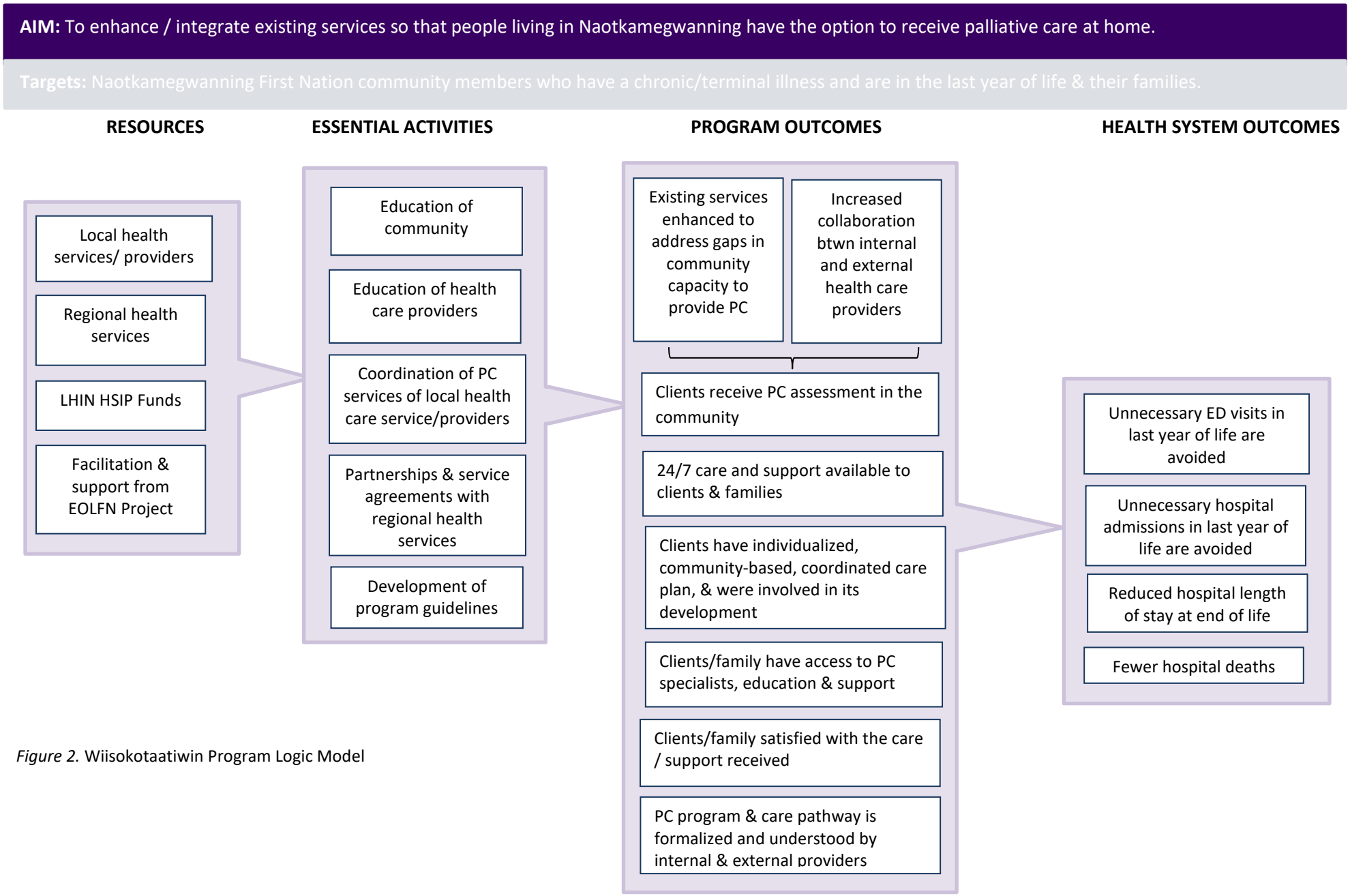

Figure 2. Wiisokotaatiwin Program Logic Model

The Wiisokotaatiwin Care Pathway[i] was developed through a series of three Journey Mapping[ii] workshops that were held with 24 health care providers who services to Naotkamegwanning community members. The workshops involved discussions of how Naotkamegwanning community members transition through the health care system as they approach end of life, and identification of barriers and solutions to improve service integration.[3]

The Wiisokotaatiwin Care Pathway (Figure 3) begins with identifying a person eligible for the program (see section 1.2.2.). Prospective clients are then informed about the program and, with their consent; a referral is made to the Wiisokotaatiwin Program Coordinator (who is also the coordinator of the Community Care Program). Any health care provider can make referrals; self and family referrals are also accepted.

Upon receiving the referral, the Coordinator visits the client to explain the program and conduct a comprehensive palliative care assessment. Once the assessment is complete, the Coordinator schedules a case conference with the client (and family) to develop a palliative care plan; members of the circle of care are invited to the case conference as appropriate (e.g., home care nurse, nurse practitioner, discharge planner, etc.). An in-home palliative care chart is implemented.

During the case conference, a care plan is developed and shared with the circle of care. The plan includes goals of care, services to be provided, procurement and storage of medications, equipment procurement, as well as a checklist of possible services that can address all domains of care. The care plan is then implemented through coordinated health service delivery. Nursing is provided by the FNIHB nurses who visits the community and know the clients and their families. CCAC provides professional health services other than nursing. The services of the visiting nurse practitioner and physician are included as needed in the care plan.

The Coordinator is the client's care manager and provides intensive case management. The Community Care program staff provide the required personal support, home making and respite care. Staff and family are instructed to call the Coordinator with any questions regarding care, changes in health status, symptom crisis, and prior to taking client to the hospital. This care support is available 24/7, and family and staff are made aware of whom to contact when the Coordinator is away from the community.

[i] A Care Pathway is a diagram that outlines the expected care for clients who would benefit by receiving palliative care. The Care Pathway is created by involved care providers, and focuses on providing clients the best palliative care and the most positive outcomes as they move between different health care providers and organizations.[3]
[ii] Journey Mapping is a process to improve the coordination and integration of care for clients as they access services from multiple programs and health care providers.[3]

There is ongoing communication amongst members of the circle of care. Reassessments are coordinated through the Coordinator and FNIHB home care nurse and adjustments to the care plan are made as necessary. If the client is transferred to hospital, the Coordinator contacts the hospital (discharge planer or ED, depending on type of hospital visit). The client is requested to bring the In-Home chart to the hospital for the reference of the hospital staff. If the hospital visit is an Emergency Room visit, a note will be placed in the In-Home chart as to reason for visit, the treatment, and any further plan. If the hospital visit is an admission, the Coordinator will be involved in discharge planning.

End-of-life care discussions are initiated with the client/family at a Palliative Performance Scale Score of 30% (or earlier if appropriate). If the client is at home, the Coordinator discusses with the client/family 'what it means to stay home' at the end of life, and what services the program can offer. A protocol for home passing is followed which includes identifying and educating family caregivers, identifying spiritual support people, completing a DNR and placing it in the in-home chart, identifying the individual responsible for pronouncement, ensuring funeral home is notified and communicating the care plan for home passing to all providers involved in the passing.

If the client is in hospital, the options for care and services in hospital and at home are explained. A client's decision to be at home initiates a case conference and care plan revisions, which include explanation of the expected physical changes and involvement of spiritual or traditional support.

After a client passes, program services continue as appropriate (e.g., a follow-up bereavement visit from the Coordinator), referrals made to community services if additional support is required. When the file is closed, the Coordinator arranges the return of equipment to agencies as required.

Box 1. Internal and External Health Care Providers, Organizations, and Services Associated with the Wiisokotaatiwin Care Pathway

Wiisokotaatiwin Program List of Services (Internal health care providers)
Community Care Program - Program Coordinator, Home Care Nurse, Personal Support Workers, Home Maker, Home Support **Netaawgonebiik Health Services** - Administration, Health Clerk/Reception, Community Mental Health Nurse, Community Health Educator, Mental Health Services, Elder Support Worker, Family Support Worker, Circle of Hope and Healing, Community Wellness Worker, Suicide Prevention/Black River Camp, Community Transportation Services
Community Health Care Providers (External health care providers)
Waasegiizhig Nanaandawe'iyewigamig (WNHAC) Aboriginal Health Access Centre, Kenora, ON - Nurse Practitioner, Mental Health & Emotional Services

Kenora Chiefs Advisory, Kenora, ON
- Psychologist, Social Worker, Mental Health Team, Spiritual Care providers

Lake of the Woods District Hospital, Kenora, ON
- Palliative Care Coordinator, Discharge Planner

North West Community Care Access Centre
-Physiotherapy, Occupational therapy, Social Work

Johnson's Pharmacy, Kenora, ON
-Medication and medical supplies

Palliative Pain & Symptom Management Program, Northwest CCAC, Thunder Bay, ON

Telemedicine Nurse, Hospice Palliative Care (St. Joseph's Care Group), Thunder Bay, ON

Community Health Care Professionals Inc. (FNIHB nursing care provider)

Shoppers Home Health Care
-Equipment Brown's Funeral Home

2. EVALUATION

2.1. PURPOSE & OBJECTIVES

This process evaluation assessed program implementation and value. Objectives and questions were:

- To document program implementation:
  - What resources were required to implement the pilot?
  - Were the 'essential activities' in the logic model implemented in the pilot?
  - Who participated in the program (number and profile of clients)?
  - What services were provided to clients (by who, when, and where)?

- To report on the accountability / success indicators that were specified in the funding proposal.

- To assess the value of the Wiisokotaatiwin Program.

2.2. METHODS

A mixed-methods approach was adopted, involving both qualitative and quantitative data.

2.2.1. Data Collection

2.2.1.1. Weekly Client Tracking Forms

Weekly client tracking forms documented service provision and hospital utilization. The type of service provided was documented as well as details on who provided each service, when, where, and how. Hospital utilization information was also recorded including the number of ED visits /hospital admissions each week (including reason), and the recorder's perceptions on whether the hospital utilization was avoidable. The Coordinator completed one form per client at the end of every week. The forms were very detailed (See Appendix B). Thus, to mitigate data collection burden, tracking data was only collected for 4 months only (May – August 2015).

2.2.1.2. Client/Family Questionnaires

End-of-pilot questionnaires assessed client (*n* = 3) and families' (*n* = 4) satisfaction with the program, whether it was meeting their needs and whether they felt the care received through the program prevented hospital visits for them. The questionnaires were brief, comprised of open and closed ended questions.

2.2.1.3. Service Provider Questionnaires

End-of-pilot questionnaires assessed health care providers' (*n* = 22) satisfaction working within the new model of care, as well as their perceptions of program value and whether it was achieving its goals. The questionnaires were comprised of open and closed ended questions and were distributed to the internal and external service providers who were involved with the pilot project.

2.2.1.4. Program Leadership Team Focus Group

An end-of-pilot focus group, guided by a series of open-ended questions, explored key informants' perceptions of the benefits and value-added of the pilot program and the new model of service delivery. Participants were members of the leadership team for the EOLFN project and included the community health educator, the health director, an Elder from the community, the Community Care Coordinator and the EOLFN project resource /liaison person. The focus group was audio-recorded, and lasted approximately 1 hour.

2.2.1.5. Program Documents

A variety of program documents were collected to assess program implementation and value (e.g., client registration forms, case conference summaries, education registration lists, program guidelines booklet, client brochure, invoices, payroll records, etc.).

2.2.1.6. Program Coordinator Interview

An interview was conducted with the Wiisokotaatiwin Program Coordinator five months after the pilot ended. The interview was semi-structured, aimed at reflecting on the status of the pilot once it ended. The interview was audio-recorded, and lasted approximately one hour.

2.2.2. Data Analysis

Quantitative data from the tracking sheets, surveys and program documents were tallied, and are summarized using frequencies and descriptive statistics. Qualitative data from the questionnaires and focus group were analyzed for emerging themes using the evaluation objectives/questions as sensitizing concepts. Illustrative quotes are presented.

2.3. RESULTS

2.3.1. Documenting Program Implementation

2.3.1.1. Resources

All of the resources listed in the Program Logic Model were in place (Figure 2).

Prior to the pilot, the community had local health services/service providers that provided the foundation for the service enhancements and were committed to the Wiisokotaatiwiin program. The community capacity development process and the journey mapping workshops previously conducted ensured the involvement and engagement of regional health care providers and palliative care experts. Internal and external providers were committed to working together to improve palliative care in Naotkamegwanning.

Start-up funding was provided by the NW LHIN ($60,000/10mths) to fund: enhanced clinical care/services consisting of intensive case management, personal support worker visits and nursing ($49,000); consultation, training and evaluation ($7,000), and equipment ($4,000). In-kind support was also provided from the EOLFN project for project facilitation (a project resource person/liaison: 0.5day/week=$4145/7mths), and a community facilitator and administrative assistance ($37,452).

2.3.1.2. Activities

Analysis of program documents indicated that each of the four essential activities (Figure 2) were also implemented.

Education. The Coordinator and a member of the EOLFN project team attended a *cultural sensitivity training* workshop in Sioux Lookout (January 13 – 15, 2015). A ½-day cultural sensitivity training workshop was delivered to external health care providers who provide service to Naotkamegwanning community members (February 27, 2015). A one-day cultural sensitivity training

workshop was also delivered to external health care providers who were providing service through the Wiisokotaatiwin program (June 2015).

Palliative care education was delivered by CERAH to health care providers through Pallium's Learning Essential Approaches to Palliative care (LEAP) course that was held in Kenora (February 27 – March 1, 2015). Twenty people attended the training, including internal and external health care providers involved in the pilot (See Accountability and Success indicators, Table 3, p.23). In addition, the program Coordinator provided education to Wiisokotaatiwin staff and clients/families as part of ongoing case management duties.

Coordination of local palliative care services & Partnerships/service agreements with regional services. This included coordination of all of the services offered through the local Community Care Program and Netaawgonebiik Health Services (See Box 1, p.13).

Two formal service agreements were made with regional health services: one with Waasegiizhig Nanaandawe'iyewigamig (WNHAC) to pay for Nurse Practitioner (NP) services offered to Wiisokotaatiwin clients; a second with Community Health Care Professionals to pay for additional and on call nursing services for the pilot.

The Thunder Bay Regional Health Sciences Centre (Cancer Centre) agreed to include Naotkamegwanning First Nation in their telehospice palliative home care project and provided the community access to the Ontario Telemedicine Network (OTN). As they are federally funded health services, First Nations community are not entitled to telemedicine. OTN was a valuable tool during community case conferences as palliative care experts from outside the community were able to join the meeting.

There were additional partnerships with MOUs or collaborations with: the First Nations and Inuit Home and Community Care (FNIHCC) program (Ontario Region), North West Community Care Access Centre (NW CCAC), Thunder Bay Regional Health Sciences Centre (TBRHSC) and Regional Cancer Centre, St. Joseph's Care Group Telemedicine Nurse, Lake of the Woods District Hospital (LWDH), Lakehead University's Centre for Education and Research on Aging & Health's (CERAH) palliative care education, Lakehead University's Centre for Education and Research on Aging & Health's Improving End-of-Life Care in First Nations Communities project (EOLFN), Wesway, and the Kenora/Rainy River Hospice Volunteer program.

Program guidelines. Two sets of guidelines were developed: i) The Wiisokotaatiwin Program Guidelines Booklet which details the Care Pathway and services involved in the pilot, and ii) The Wiisokotaatiwin Client Brochure (a condensed version of the booklet).[10] The guidelines were disseminated to all organizations involved in the pilot.

2.3.1.3. Program Participants

Seven Naotkamegwanning First Nation community members were identified as potential clients for the pilot program. One member died early in the pilot, and did not receive services through Wiisokotaatiwin. Therefore, this evaluation focuses on the services received by six clients. Four of the six clients were on the program for the duration of the pilot (November – August 2015) and two additional clients were registered toward the end of the pilot (May/June 2015).

All clients were referred to Wiisokotaatiwin through the Community Care Program. See Table 1 for the demographic characteristics of program clients

Table 1. Demographic Characteristics of the Wiisokotaatiwin Clients (*N* = 6)

Characteristic	***n***[a]
Gender	
Male	2
Female	4
Age	
60 – 69	1
70 – 79	2
80 – 89	1
90 – 99	2
Palliative Performance Scale Score (%) on admission to program	
50	1
60	3
70	2
Diagnosis/ Reason for Referral	
Parkinson's Disease	1
Diabetes (w complications)	4
Frail elderly	1
Living arrangement	
Lived at home alone	2
Lived at home with adult children	3
# of local family care givers involved	
0 – 1	4
2 – 3	0
≥ 4	1

[a] Some cells do not sum to six due to missing data

2.3.1.4. Services Provided

Palliative Care Assessments, Case Conferences, and Care Plans. All six clients received a palliative care assessment in the community. A palliative care case conference was held for each client (in their home or at the Band Administration office), and internal and external health care providers attended (sometimes via OTN). An integrated care plan was developed for each client and the client/family were

involved in its development.

Direct Client Services. Analysis of the weekly tracking sheets (May – August 2015) indicated that clients received an average of 51 hours of direct client service per month (range = 16 – 103hrs).[iii] Most of those hours are accounted for by nursing and home support (89%) and respite (9%) services (i.e., the enhanced services supported by the pilot funding). See Table 2.

Almost half (40%) of the direct client services that were recorded were delivered outside of the regular HCCP hours (i.e., enhanced services). See Figure 4. Home support visits (PSW + HM) accounted for most (81%) of the evening/weekend hours. Respite was also most often provided on evenings and weekends.

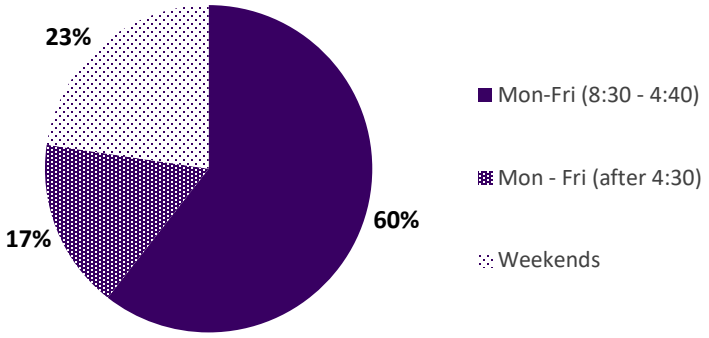

Figure 4. Proportion of Direct Client Services Delivered to Wiisokotaatiwin Clients by Noatkamegwanning Community Care Program by Day and Time (May – August 2015)

Table 2. Direct Client Services Provided to Wiisokotaatiwin Clients (May - August 2015)

Service Provider	Services Provided	Average[a] weekly hrs (Range)	Total hrs
Nursing			
Home Care Nurse	Monitoring Education Medication Review Counselling/Support	2 (0 – 3.5)	132.5
Nurse Practitioner	Assessment & Monitoring Counselling/Support	2 (0 – 3)	138.5 [b]
Home Support			
Personal Support Worker	Personal Care Monitoring Medication Reminders Medication Delivery Medical Transportation	3 (0 – 7)	278.3

[iii] Average = (total # of hours / total # of clients)/total months: (1211.3/6)/4 = 50.47

Service Provider	Services Provided	Average[a] weekly hrs (Range)	Total hrs
	Help with PT exercises		
Home Maker/ Home Support Worker	Cleaning & Meal Preparation Personal Support Medication Reminders Medication Assistance Medical Transportation / Yard work Install Supportive Equip.	6 (0 – 14)	523
Other			
Respite Worker	2 clients received respite: Client a = 32hrs; Client b = 77hrs (visiting, overnight stays, & homemaking)	NA	109
Occupational/ Physical Therapy (CCAC)	OT assessed client for walker / PT trained PSW to do exercises w client	NA	4
Medical Transportation	Med. Driver /Alternate Transportation to hospital & med. Appointments	NA	9
Elder Support	Grocery shopping in Kenora Assist with government forms	NA	8
Escort	Accompany client to hospital & provide translation	NA	9
Total Direct Client Services Recorded (May – August 2015) ……			**1,211.3**

[a] The statistical mean

[b] The NP visited client's weekdays after 4:30 – she would do her home visits at the end of her day – after completing her normal duties at the clinic. It is important to note that the NP visited after hours for her convenience and not because the client required after hours visits. Only the essential after hours visits are included in Figure 4 (i.e., NP hours removed).

Case Management / Program Coordination. The pilot funding also supported the role of the Wiisokotaatiwin Coordinator. Analysis of the program documents revealed that 812 hours were spent on intense case management and program coordination for the pilot period (November 1, 2014 – August 31, 2015).

The weekly tracking sheets suggest that the Coordinator was a key component of the Wiisokotaatiwin Program. Most of the Coordinator's time was spent on case management (palliative care assessment/reassessment, care coordination/scheduling appointments, referrals and linkages, getting medical/pharmaceutical supplies/equipment, and record keeping/data collection). Much of the Coordinator's time was also spent on communicating with clients/family and other members of the circle of care.

The Coordinator was also on-call via cell-phone for families, clients, and program staff. Although not many after hour calls were received, the ones that were received needed to be dealt with immediately.

For example, locating and delivering medications that were not delivered to client's home avoided clients having to go to the hospital to receive their medications.

2.3.1.5. Hospital Utilization

The weekly tracking data (May – August 2015) indicated that four clients were admitted to hospital during the 4-month tracking period. All admissions were deemed unavoidable as the presenting problems were acute and/or complicated medical issues (e.g., unexplained pain). Lengths of stay ranged from 10 – 31 days, with one client dying in hospital. See Table 3 (System Level Indicator) for more details.

The weekly tracking data also indicated that three Emergency Department visits were avoided during the 4-month tracking period. Two instances were medication related (i.e., Wiisokotaatiwin Coordinator located and delivered medications that were not delivered -- the family would have had to bring client to the hospital to receive medications otherwise). One instance was an after-hours crisis call, the Coordinator visited a distressed client at home and calmed them (thus, avoiding a hospital visit).

The tracking data also indicated that one hospital admission was avoided during the 4-month tracking period. A client went to hospital with bladder problems, but was able to return home because catheter care was provided in the client's home through the Wiisokotaatiwin program.

Illustrative Case Summaries

Illustrative case summaries were created to illustrate the findings from sections 2.3.1.3. – 2.3.1.5. To protect the anonymity of the clients on the program, direct case summaries were not possible. Thus, illustrative case summaries were created based on an aggregation of the data collected through this evaluation. The resultant composite case studies are not real people; they are illustrations to reflect the people who were on the program, and their care plans and care pathways. See Box 2.

Box 2. Illustrative[a] Case Scenarios of the Wiisokotaatiwin services provided to clients during the pilot.

Illustrative Case Summaries of Services Provided to Clients

Edward is 90 years old; he is frail, and mostly homebound. Edward lives at home with his adult daughter who works full time, and cannot provide Edward with much support during the days and evenings. Edward registered with Wiisokotaatiwin at the beginning of the pilot, at which time he and his daughter attended a case conference where they and the health care providers involved in Edward's care developed an integrated care plan.

His care plan involved two nursing visits a week: the Home Care Nurse would visit on Mondays, and the NP on Thursdays. Edward appreciated that nursing schedule because it allowed for the anticipation of possible problems that might arise over the weekend, and carried him through until Monday when the Home Care Nurse would visit again. Thus, the NP visits were preventative and helped alleviate any anxieties that Edward had about his health status going into the weekend. Edward also received four visits a week from a personal support worker and three visits a week from a homemaker (different days, including some evenings and weekends). They would help Edward with personal care, cleaning, and meal preparation. Those visits helped alleviate some of Edward's daughter's anxieties about her dad being home alone.

The Wiisokotaatiwin Coordinator was active in Edward's case management and was often busy arranging medical appointments, and making referrals (e.g., to Elder's Support to help him get groceries and complete government forms, to CCAC for assessment for a walker etc.). Edward knew that he could call the Coordinator on her cell phone if he needed to in the evenings or during the weekend, which also helped alleviate his anxiety. The Coordinator also arranged for respite visits over 2 weekends when Edward's daughter had to leave the community to be with another family member who was in the hospital.

Mary is 82 years old; she has diabetes with kidney complications. Mary lives with her adult son, he and Mary's three other adult children are involved in her care. She registered in the pilot program in May, and she and her four children were involved in the development of her integrated care plan (the case conference was held at Mary's home with the program coordinator and NP in attendance).

The care plan involved two nursing visits a week (different days). The nurses provided monitoring and support, and some health education to Mary and her children. The PSW visited twice a week to help with personal care, PT exercises, and to do medication reminders every second week. A homemaker visited once a week to help with housekeeping. The program coordinator was active in Mary's case management making referrals (e.g., to CCAC (PT), diabetic foot care, etc.), and arranging for Mary's needs to be met as they arose (e.g., ordering medical supplies/equipment, arranging for medication delivery, and having grab bars installed in the home as Mary had a couple of falls at home).

One day Mary's son called the Wiisokotaatiwin Coordinator because he was anxious as Mary began experiencing increased pain. The Coordinator consulted with the health care nurse and the NP who instructed the family to call 911 if the pain continued to increase. The pain did increase and Mary was admitted to the hospital in Kenora for the unexplained pain and an electrolyte imbalance. She stayed there for 20 days, and during her stay, the program coordinator consulted with the hospital discharge planner to get updates on Mary's status. The coordinator also consulted with the family, the home care nurse, and NP to keep them updated and discuss care plan revisions. When Mary was stable enough to go back home, her hospital discharge was planned collaboratively with the Wiisokotaatiwin Coordinator and her integrated care plan was revised to reflect her increased need.

[a] To protect the anonymity the people on the program, these are not actual clients. Rather, the cases were created as illustrations based on an aggregation of the data. These cases do reflect the people and care plans of the six clients who were on the program.

2.3.1.6. Post-Pilot Services

As of October 2015, there were five clients on the program. The community had to cut back on the services those clients received since the pilot funding ended. The clients were continuing to get one nursing visit a week and one NP visit a week (different day). Naotkamegwanning Health Services was paying for the continued NP service. Naotkamegwanning First Nation was also continuing to fund the on-call cellphones using FNIHB funds.

Of the five clients, three were stable at home and managing with HCC. One client needed 24/7 care, and was thus admitted to long-term care. One client had been hospitalized several times, but wanted to be cared for at home. A new care conference was held, and a new care plan created. The family was getting some respite care along with the PSW services during the week and nursing visits described above. A schedule of family members to help was made at the care conference; one family member took time off work to care.

As of February 2016, one more client had died. The cellphones continued to be funded through the First Nation, but enhanced services were no longer being funded.

2.3.2. Reporting on Accountability & Success Indicators

In the application for the H-SIP funds, 17 program level and seven system level indicators were specified (See Appendix A). Table 3 reports on each of those indicators.

Table 3. Accountability and Success Indicators Specified in the Wiisokotaatiwin Program Pilot Funding Proposal: A Pre-Post Pilot Comparison

Indicator	Value	
	Before Pilot	After Pilot
Program Level		
More residents in Naotkamegwanning receive palliative services at home for advanced chronic disease and end of life	0	6 (Source: Program Documents – Registration forms + Tracking Sheets)
Clients receive a palliative care assessment in community when identified	0	6 (Source: Program Documents – Registration Forms)
Palliative care case conferences are held that include local and external health care providers with pilot partners	0	6 (Source: Program Documents: Case Conference Summary Forms)

Indicator	Value	
	Before Pilot	After Pilot
Integrated care plan is developed and implemented.	0	6 (Source: Program Documents: Case Conference Summary Forms)
Cost of having a palliative care nurse on-call for evening and weekends as required.	unknown	**$1,752:** <u>On call nursing services (Nov – Aug 2015):</u> - 2 weekends on call with no service: (Fri 9pm–Mon 9pm x2): 144hrs x $3.00 = **$432.00** - No calls were received, partially because the coordinated and comprehensive process established by the program helped identify client needs, and the nurses were able to prepare the clients and families during regular business hours. Crises were largely avoided. <u>Nursing services (Nov – Aug 2015):</u> - 3 days of service = **$1320.00:** - training of PSWs and family members (2 days) - Hours accumulated by CHN who worked late for the Wiisokotaatiwin clients after her regular CHN duties + administrative time required for the program (phone calls, paper works, etc.) (1 day) (Source: Program Documents: On-call nursing service invoices)
Cost of palliative care nursing services is known (days, evenings, nights, weekends) Track Number of hours of service and type of service	unknown	**Nurse Practitioner (Nov – Aug 2015):** **$3,500** - $350/month X 10 months (Source: Program documents - invoices) **On call Nursing (Nov – Aug 2015):** **$1,752** (See row above) **Home Care Nurse (May – Aug 2015)[a]:** **$5,300**: Weekday (8:30 – 4:30) = 126 hrs Weekday (after 4:30) = 6.5hrs Weekend = 0 hrs *Total hrs (May – Aug)* = 132.5 hrs

Indicator	Value	
	Before Pilot	After Pilot
		Total wages (May – Aug) = (132.5 hrs x $40/hr) (Source: Tracking sheets (hrs) + Program Documents (wage) See Table 2 for types of service provided by NP and HCN. See row above for On call nursing services.
Cost of PSW and homemaker services is known (days, evenings, nights, weekends) Track number of hours of PSW and type of work and time of day	unknown	**Personal Support Worker (May – Aug 2015)[a]:** **$4,783.98**: Weekday (8:30 – 4:30) = 171.3 hrs Weekday (after 4:30) = 75hrs Weekend = 32 hrs *Total hrs (May – Aug)* = 278.3 hrs *Total wages (May – Aug)* = $4783.98 (278.3 hrs x $17.19/hr) (Source: Tracking sheets (hrs) + Program Documents (wage) **Home Maker (May – Aug 2015)[a]:** **$5,753.00**: Weekday (8:30 – 4:30) = 289.5 hrs Weekday (after 4:30) = 78.5hrs Weekend = 155 hrs *Total hrs (May – Aug)* = 523 hrs *Total wages (May – Aug)* = $5753 (523 hrs x $11.00/hr) See Table 2 for types of service provided by PSW and HM. (Source: Tracking sheets (hrs) + Program Documents (wage)
Cost of Respite Care services is known (days, evenings, nights, weekends) Track number of hours of PSW and type of work and time of day	unknown	**Respite Worker (May – Aug 2015)[a]:** **$1,199.00**: Weekday (8:30 – 4:30) = 37 hrs Weekday (after 4:30) = 16hrs Weekend = 56 hrs *Total hrs (May – Aug)* = 109 hrs *Total wages (May – Aug)* = $1199 (109 hrs x $11.00/hr) See Table 2 for types of service provided. (Source: Tracking sheets (hrs) + Program Documents
Cost of professional services to support palliative home care is known (PT/SW/OT etc.) (days, evenings,	unknown	Hours of Professional Services by CCAC (May – Aug 2015)[a] OT: 1hr PT: 3 hrs See Table 2 for types of service provided.

Indicator	Value	
	Before Pilot	After Pilot
nights, weekends) Track number of visits and reason for referral		(Source: Tracking sheets)
Cost of medications (oxygen) and equipment/supplies to support palliative home care is known	unknown	<u>Medical Equipment/Supplies:</u> **$4,000:** - includes: a hospital bed, a wheelchair, patient room equipment (e.g. overbed table), bathroom supplies (e.g. shower commode), and incontinence supplies (e.g., briefs). (Source: Program documents (Shoppers Home & Health Care Invoice) <u>Administrative Equipment:</u> **$1016.79** - 2 cell phones: one for the program coordinator and one for the home care nurses so that they could be on-call for clients and families.
Cost of client/family transportation related to palliative care is known	unknown	Medical Transportation Hours (May – Aug 2015)[a]: - 9 hrs Alternate Transportation/Medical Driver (provided transportation to hospital/medical appointments) - 2.5 hrs PSW/HM (provided transportation to medical appointments) - Paramedics transported 4 clients to hospital (Source: Tracking sheets)
Hours of Wiisokotaatiwin program coordination is known	Unknown	812 hours: 460 hrs (20 hrs/wk for 23 weeks for Nov.1 2014 - March 31 2015) + 352 (16 hrs/wk for 22 weeks for April 1 – Aug. 31 2015) (Source: Program documents (Payroll records)
HCC attendance at palliative care case conference	0	6 (Source: Case Conference Summary Sheets)
HCC attendance at palliative care/EOL discharge planning	0	HCCP attendance at discharge planning May – Aug 2015[a]: - For all (4) hospital admissions, the Wiisokotaatiwin Coordinator consulted with the hospital discharge planner (Re: client status update).

Indicator	Value	
	Before Pilot	After Pilot
		- Discharges were planned collaboratively for 2 clients. One client died while in hospital. (Source: Tracking Sheets)
Education for direct care providers	6 PSW received palliative care for Front Line Workers training	3 HCCP providers + Wiisokotaatiwin Coordinator completed LEAP (training was funded with H-SIP $) 6 HCPs external to HCCP completed LEAP (training funded by partner organizations) (Source: Program documents – LEAP sign in sheets)
Clients who would benefit by palliative care are identified earlier in their journey by Home and Community Care Program (prior to 50% on the PPS)	3 clients identified as eligible for Wiisokotaatiwin	7 clients identified (one died early in the pilot; received no services). All 6 clients on the program were identified prior to 50% PPS. (Source: Program documents - Client registration forms).
HCCP consultation with palliative care experts	0	For all 6 clients the Coordinator reported she had extensive consultation with other professionals in the circle of care (e.g., physician, NP, discharge planner, HC Nurse, etc.). (Source: Tracking Sheets + Coordinator Interview)
System Level		
Wiisokotaatiwin Program	No palliative care program description relevant to First Nations Communities	Program description sent to all agencies involved in the pilot. Grand rounds done at hospital for physicians and nurses. Information on program provided to ED.
The number of ED visits by clients in the last year of life (registered with Wiisokotaatiwin) Track reason for visit	Unknown	# of ED visits (May – Aug 2015)[a]: 4 Reasons for visits: - abdominal pain was being monitored at home; NP ordered HCN to call 911 if pain increased. - chest pain (client took nitro 5x at home with no relief) - excessive nose bleeding - bladder problems

Indicator	Value	
	Before Pilot	After Pilot
		(Source: Tracking sheets)
The number of hospital days for client in the last year of life (registered with Wiisokotaatiwin) including reason for admission.	Unknown (average EOL admission in Kenora/Rainy River is 21 days)	# of hospital days (May – Aug 2015)[a]: 4 clients were admitted to hospital: *Reason for Admission* — *Length of stay* Chest pain — 10 days Abdominal pain — 16 days Nose bleed — 21 days Pain+ confusion — 31 days (Source: Tracking sheets)
Discharges from hospital are planned collaboratively with HCC	0	During the 4 month tracking period, 3 Wiisokotaatiwin clients were discharged from hospital – 2 of those were planned collaboratively with HCCP[a] (Source: Tracking sheets)
Fewer Hospital Deaths	5 in 2014 for eight months	2 in 10 months (Source: Tracking sheets)
HCCP health care providers receive palliative care education	6	10 (Source: Program documents – LEAP sign in sheets)
External health care providers receive palliative care education (LEAP)	0	6 (Source: Program documents – LEAP sign in sheets)

[a] These values were obtained from the weekly client tracking sheets. To ease data collection burden, the detailed tracking data was only collected for 4 months (May – August 2015). Thus, exact hours/cost is only available for that sample period.

2.3.3. Assessing Program Value

In the funding proposal, it was stated that program value would be demonstrated by internal and external health care providers' agreement that the pilot met 14 objectives (See Appendix A). The end-of-project questionnaire asked health care providers (HCPs) to indicate their level agreement with statements reflecting those 14 objectives. As can be seen in Table 4, most respondents agreed with the statements.

Table 4. Internal and External Health Care Providers (HCPs) Level of Agreement with Pilot Objectives

Objective	**Proportion of respondents who agree[a]**	
	Internal HCPs (N = 8)	**External HCPs** (N = 14)
Clients have the choice to receive palliative care at home	7/7	14/14
Clients receive quality palliative home care in Naotkamegwanning	7/7	7/10[b]
Families are more educated and supported in their role as caregivers	7/7	10/10
Local HCPs are more confident in the delivery of palliative care	6/6	12/13
External HCPs provide more culturally relevant care	5/5	13/13
Health system organization and care processes are improved to provide palliative home care in Naotkamegwanning	--	14/14
Residents of Naotkamegwanning have improved access to palliative care	7/7	14/14
Clinical information sharing among health service provider agencies has improved	7/7	14/14
Improved accessibility of health care using technology (i.e., OTN and tablet)	3/4	8/9
Better communication and continuity of care between primary care and palliative care specialists	6/6	7/8
Fewer unnecessary ED visits	4/4	3/4
Fewer avoidable admissions to hospital	5/5	5/5
Increased adoption of best practices for palliative care	6/6	11/11
System integration is improved to utilize resources more efficiently	7/7	13/13
Naotkamegwanning Model of Care is transferable to other First Nations communities	6/7	12/12

[a] Numerator = # of respondents who "Agreed" or "Strongly Agreed" with statements reflecting these objectives. Denominator = Total # of respondents who offered an opinion on the statement. Those who responded "Don't know/No basis to judge" (i.e., those who felt they could not comment) were not included in the tally.

[b] Those who disagreed had completed the survey once the pilot was finished and explained, for example, that: "While the pilot was running care and access to care was very good. Since the pilot has finished and funding is no longer available access to care has now decreased in the community significantly".

The survey findings also indicated that clients, family members, and health care providers were satisfied with the program:

- All service providers surveyed (22/22) indicated they were 'satisfied' or 'very satisfied' working within the new model of care of the Wiisokotaatiwin Program.
- All family members (4/4) and most clients (2/3) surveyed indicated they were 'satisfied' or 'very satisfied' with the services and supports received through the Wiisokotaatiwin Program
- All family members felt that the supports they received through the program met their needs.
- Most clients (2/3) and family members (3/4) felt that the program was meeting client's needs.

In addition, analysis of the focus group and open-ended survey data indicated that stakeholders perceive Wiisokotaatiwin to be a valuable program, and that it made progress toward its intended outcomes during the pilot (Boxes 3 & 4). However, there was concern that without continued funding, the program was not sustainable (Box 5).

Box 3. Illustrative Quotes for the Qualitative Theme 'Wiisokotaatiwin is a Valuable Program'

Wiisokotaatiwin is a valuable program…

"This is a good start to a much needed program." (Family Member)

"I think it's worth continuing the services and staff training. Keeping that communication open with everyone. Because even if just one person wants to stay home or come home from hospital, it's worth having those services. We'll be prepared and everyone will know what each other's role is." (Leadership Team Member)

"The Wiisokotaatiwin Program is an excellent example of community driven palliative care service coordination. They have overcome barriers to service delivery by thinking outside of the box, looking within to existing community services and reaching out where needed to establish necessary linkages. All of this was done at very little cost tot health system – although is should be acknowledged that the people involved at the community level have worked exceedingly hard to make the program the success it is today."

Box 4. Illustrative Quotes for the Qualitative Theme 'Positive Outcomes of the Program'

Positive outcomes of the Wiisokotaatiwin program …

"This was a good program to start the conversation of support for sick and elderly in their home ...I feel the program gave the community confidence to move forward". (Internal Health Care Provider)

"From the service delivery point of view we are able to provide services after hours and weekends." (Leadership Team Member)

"I think for me, one of the major positive things that happened was creating those partnerships and starting that communication with our health care providers." (Leadership Team Member)

"We are only seeing admissions for acute problems not being able to be handled in community and soon as everything is stable home is an earlier option then staying in hospital or moving out of community to long-term care." (External Health Care Provider)

"People have the option of remaining in an environment that is comfortable for them and with family/friends nearby. It's cost effective - staying at home with the appropriate support is more economical than the cost of being institutionalized." (External Health Care Provider)

Box 5. Illustrative Quotes for the Qualitative Theme 'The Need for Sustained Funding'

The need for sustained funding…

"I enjoyed the model, but without the funding the model is not sustainable." (Internal Health Care Provider)

"The pilot project created a fantastic program and many from the community were able to benefit from it. It is a program that can be transferred to other communities. The amount of extra funding needed to sustain the program was minimal and saved the healthcare system money in the long run. Need one of the governments to commit to ongoing palliative care funding." (External Health Care Provider)

"I think there is a big need to keep funding because we don't have a budget for it. And, I think we've proven that there is a need. Like right now especially, with our elders that are sick at home. Right now is when we need that funding because there are caregivers looking after their parents and sometimes they need respite and other services." (Leadership Team Member)

3. DISCUSSION

This evaluation sought to document the implementation, and assess the value of the Wiisokotaatiwin Program pilot. A mix of quantitative and qualitative data were collected and analyzed, and the findings were presented in Section 2.3. Section 3.1 below discusses the findings in relation to the overall objectives of documenting program implementation and assessing program value.

3.1. DISCUSSION OF FINDINGS

A comparison of the implementation findings (Section 2.3.1.) to the program logic model (Figure 2) indicates that the program was implemented as intended. All resources were in place, essential activities were implemented and existing services were enhanced, integrated and provided to the intended clients.

3.1.1. Program Implementation

3.1.1.1. Resources & Activities

In terms of resources, the findings suggest that local palliative care service providers, regional health services, funds and program facilitation/support were required to implement the pilot.

In terms of services, there were sufficient infrastructure and health services to allow for the development of the local palliative care program. Specifically, there were local palliative care service providers (e.g., health clinic, HCC program, etc.), and regional health services were available to Naotkamegwanning community members. Those two elements allowed for the adoption of a service enhancement and integration program model.

In addition, extensive facilitation and support was provided to the community through the EOLFN research project. The Wiisokotaatiwin Program was the culmination of three years of community capacity development that was done through the project (See Section 1.1.3.). In addition to supporting and facilitating the development of the local palliative care program, the EOLFN project also facilitated and supported program implementation through in-kind contributions of a project resource person, a community facilitator and administrative support (See Section 2.3.1.1.).

Finally, though the community developed its palliative care program with the support of the EOLFN project, it could not implement the program without service delivery funds. The HSIP funds provided by the NW LHIN for the 10-month pilot period, allowed for the enhancement of the existing services (e.g., home care nurse, nurse practitioner, home support, intense case management, etc.).

In terms of the essential activities (Figure 2), the findings demonstrate that each of them was implemented. In terms of education, cultural sensitivity training was delivered to external health care

providers. This is an important contribution of the pilot as is educating external providers on cultural safety and competency and about the First Nation community's protocols, practices, and health care services is a key element of improving end-of-life care in First Nations communities.[3] Palliative care education was also provided to internal and external health care providers. This is an important contribution of the pilot as another key element of developing palliative care in First Nations communities is educating front-line providers about palliative care.[3]

The palliative care services of local providers were coordinated through the Wiisokotaatiwin Coordinator. In addition, partnerships with regional health services were implemented and two formal service agreements were made (See Section 2.3.1.2.). These agreements funded the on-call nursing and NP services, which were important elements of the service enhancement/integration model.

Another critical collaboration enabled the community to access telemedicine (OTN). This is also an important contribution of the pilot because OTN provides a mechanism to facilitate the integration of services and the development of integrated care plans. Generally speaking, integrating telemedicine in First Nations communities is an important element of developing palliative care capacity. It is a valuable resource for accessing specialist palliative care consultations for people living in First Nations communities. Telemedicine is also a valuable resource for connecting internal and external health care providers for case conferences.[3] In the case of Wiisokotaatiwin, the evaluation findings indicate that HCPs were involved in Wiisokotaatiwin case conferences through OTN (See Section 2.3.1.4.).

Finally, the program guidelines were developed and disseminated as part of the pilot. This is an important element of program implementation as the program guidelines formalize the palliative care program and Care Pathway, and describe the palliative care program in detail and how it works in the community.

Each of the above activities was considered essential in order to implement the program and achieve its intended outcomes. These activities were either part of or the result of preparatory work done through the EOLFN research project (See Section 1.1.3.).

3.1.1.2. Clients & Services

The program was targeted to Naotkamegwanning First Nation community members who had a progressive chronic or terminal illness and were in their last year of life. Six clients were on the pilot program – all of them had a chronic illness (including frailty) with PPS scores between 70 – 50%, with a prognosis of expected decline to 0% within 1 year. Thus, the program was successful in reaching its intended population.

Seven community members were identified as potential clients for the program during the 10-month pilot period (see section 2.3.1.3.); indicating a need for a local palliative care program in Naotkamegwanning.

In terms of services, the pilot proposed to integrate and enhance existing services so that people living in Naotkamegwanning had the option to receive palliative care at home. The service provision findings suggest that the services were integrated and enhanced as intended. For example, the Wiisokotaatiwin Coordinator was often making referrals and linkages for clients to the project partner organizations (integration of services). Most of the services documented during the 4-month tracking period were an enhancement of the existing HCCP services (e.g., NP services, on call nursing, Wiisokotaatiwin program coordinator/case manager, and additional home care nurse and home support hours), and provided to clients outside of the existing HCCP hours (enhanced services). See Section 2.3.1.4.

3.1.2. Program Value

Though the pilot period was short (i.e., 10 months), the findings suggest that the pilot met each of its intended program level outcomes, and was making progress toward the system level outcomes.

3.1.2.1. Program Level Outcomes

There were eight program level intended outcomes specified in the logic model (Figure 2). The findings suggest that all were met during the pilot. The service provision data indicate that during the pilot existing services were enhanced to address gaps in community capacity to provide palliative care (e.g., enhanced nursing, home support and respite services); however, due to lack of sustained service delivery funds, that enhanced services were unable to be provided once the pilot ended. The focus group and health care provider's questionnaire data indicate that the pilot lead to increased collaboration between internal and external health care providers, and that the palliative care program and care pathway is formalized and understood by the health care providers.

The service provision data indicate that all clients received a palliative care assessment in the community; and that an individualized, community-based, coordinated care plan was developed and implemented for each client. Those data also indicate that during the pilot period, the intense case management, the enhanced service hours (evenings and weekends), and the program on-call cell-phones helped ensure that 24/7 palliative care services and supports were available to clients and their families. The client/family questionnaire data indicate that clients and families were satisfied with the palliative care services/supports received through Wiisokotaatiwin, and that they felt their needs were being met.

The questionnaire data indicate that the clients, families, and health care providers thought the program was meeting its objectives. The qualitative findings suggest that clients/families and staff felt the program was valuable and a needed service in Naotkamegwanning (Boxes 3 & 4), but unsustainable without service delivery funding (Box 5). The post-pilot interview, along with the survey findings indicate that the program model was not able to continue after the pilot funding ended (See Section 2.3.1.6. and see note b, Table 4).

3.2.1.2. Health System Outcomes

There were four health system level intended outcomes specified in the logic model (Figure 2). The findings suggest that progress was being made toward those outcomes. The service provision data indicate that at least three unnecessary ED visits were avoided, and one unnecessary hospital admission was avoided during the 4-month tracking period. See Section 2.3.1.5., Box 2, and Table 3.

Reducing hospital deaths was also an intended outcome of the pilot. This outcome however, was difficult to demonstrate during the 10-month pilot period.

3.2. LIMITATIONS

A few limitations of the evaluation are of note.

There is the potential for human error in the completion of the weekly tracking sheets because of the way there were being completed (i.e., by very busy service providers above and beyond documentation they were completing for FNHIB and the NW LHIN). In an effort to minimize error, the EOLFN project resource/ liaison person assisted with completing the tracking sheets.

Despite attempts, the evaluation team was unable to access LWDH utilization data for the Wiisokotaatiwin clients. While the tracking sheets did document hospital utilization, that was only done for a sample period (4 months). Thus, it is difficult to assess the system level outcomes. Relatedly, a 10-month pilot period is too short a period to effectively evaluate the system level outcomes. The pilot had a small number of clients (n = 6), and the program eligibility criteria was for a client to be in the last year of life. However, the pilot period was less than one year; thus, few clients died while on the program.

3.3. SUMMARY OF EVALUATION FINDINGS

This evaluation demonstrated the success and accountability indicators that were outlined in the funding proposal. The findings also demonstrate the program was implemented as intended, and that there was a need for the program in Naotkamegwanning. The findings also demonstrate progress toward its intended outcomes indicating value added at both the program and system level.

At the program level, all of the intended outcomes were achieved during the pilot. At the system level, progress was made toward some of the intended outcomes (i.e., findings suggest that unnecessary ED visits and hospital admission were avoided during the pilot).

The evaluation findings also suggest that clients/families and health care providers were satisfied with the program, perceived it to be meeting its objectives, and thought it was worthwhile. However, there was a concern that the program was not sustainable without continued funding.

Overall, the findings suggest that the main goal of the program (to enhance and integrate existing services so that people living in Naotkamegwanning have the option to receive palliative care at home) was met during the pilot. A key element of the success of the pilot was the capacity development work with the EOLFN project. The work through the EOLFN project laid much of the groundwork for the pilot, and the EOLFN team provided facilitation and support to implement the program as well.

Though the EOLFN project was important in developing the palliative care program, and supported the implementation, the LHIN pilot funding was instrumental in implementing the program. The service delivery funds from the NW LHIN allowed for the enhancement and integration of services so that palliative care services and supports were available 24/7 in Naotkamegwanning. However, that level of service could not be sustained once the pilot funding ended.

3.4. DISCUSSION AND IMPLICATIONS

The findings of the pilot project illustrate that the Naotkamegwanning community had both the motivation and capacity to care for their very sick community members at home. The LHIN funding provided them the needed opportunity, as did support from the EOLFN project team at Lakehead University. As a case study, this pilot project suggests that other First Nations communities with similar motivation, capacity and opportunity could implement a local palliative care program, tailoring their program to their unique community needs, local resources and regional context.

To support creation of a supportive policy context for local palliative care development in First Nations communities, the "Improving End-of-Life Care in First Nations Communities" project created two policy reports,[11-13] which can be accessed on the EOLFN website at http://eolfn.lakeheadu.ca/project-results/reports. The pilot project at Naotkamegwanning illustrates the relevance of these policy reports and their guidelines and recommendations, which will be highlighted below.

The first policy document, "Provision of Palliative Care to Ontario First Nations Communities: An environmental scan of Ontario Health Care Providers Organizations" (2013) was based on data collected from the regional End-of-Life Care Networks, Aboriginal Health Leads from the Local Health Integration Networks and key informants from health service delivery programs. This report recommends that the 14 LHINs work with First Nations communities to facilitate the sharing of innovative practices for providing palliative care and to promote access to culturally relevant palliative care education, training, coaching, and mentorship for First Nations service providers. In regional planning, the LHINs can also clarify their mandate in planning for the provision of palliative care services in First Nations communities; ensure that palliative care in First Nations communities is addressed as a priority in regional palliative care planning and that efforts are made to build local capacity in First Nations communities. Most importantly, the report emphasizes the need for LHIN's to work out collaborative agreements with the federal government and other service providers as necessary to meet the identified needs for palliative care services on First Nations communities.

The North West LHIN and the North West Regional Palliative Care Program are to be complemented on taking leadership on several of these issues and providing funding the Naotkamegwanning pilot project. However, more needs to be done to create access to quality palliative care for First Nations communities across our region and province and sustainability of programs.

A second policy document, "A Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities,"[12] provides ten components based on the principles of equity and social justice. Three of the components are overarching policy guidelines for palliative care programs in First Nations communities:

1) ***The policy endorses a unique philosophy, definition, and, community-based process for providing palliative care in First Nations communities that is distinct from a westernized, medicalized or urban model of palliative care.***

2) ***The policy needs to be founded on collaboration across federal, provincial and territorial jurisdictions that will create equity of access to palliative care for people living in First Nations communities as compared to other citizens of the province or territory.***

3) ***The policy allows for local customization of the eligibility criteria for palliative care services and customization of the funding and accountability processes.***

The experience of Naotkamegwanning illustrates the application of these guidelines. The development of the Wiisokotaatiwin Program was grounded in community values and principles and based on Naotkamegwanning's understanding of health, illness and death. There was local control and implementation of the program through the development of a Leadership Team comprised of community members, Elders and internal health care providers, which built on local strengths and capacities. The program also promoted an integrative approach to care for clients and families, which supported the choice of setting of care. The program emphasized and addressed the need for culturally safe care for community members by external health care providers and service agencies.
A major focus of the pilot project was the integration of knowledge from both the westernized health care system along with Indigenous philosophy, values and beliefs. Through several Journey Mapping workshops, care providers and programs from both the provincially and federally funded health care system came together to support community members from Naotkamegwanning. Through this process, a care pathway was developed which overcame numerous barriers to care that were embedded in jurisdictional issues.

Lastly, the pilot project allowed for the customization of the program through local control and provided the community with the opportunity to be creative in service provision and in the development and strengthening of partnerships within and external to the community. There was strong collaboration with First Nations health care providers, along with respectful relationships with external resources, services and decision makers.

The Wiisokotaatiwin Program provides a strong example of the process of developing a palliative care program in a First Nations community as well as the components, which would make it successful. While this program was developed from the grassroots of the community, its success would not have been possible without external support from funders and policy makers. These key components have many implications for future LHIN planning, integration and funding of local health care for First Nations communities.

References

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9. Improving End-of-Life Care in First Nations Communities project website: www.eolfn.lakeheadu.ca

10. Netaawgonebiik Health Services Home & Community Care and Long-Term Care. W*iisokotaatiwin Program Guidelines.*

11. Improving End-of-Life Care in First Nations Communities Research Project (April 2013). *Provision of Palliative Care to Ontario First Nations Communities: An environmental scan of Ontario Health Care Providers Organizations.*

12. Improving End-of-Life Care in First Nations Communities Research Project (January 2015). *A Framework to Guide Policy and Program Development for Palliative care in First Nations Communities.*

13. Improving End-of-Life Care in First Nations Communities Research Project (December 2014). *Recommendations to Improve Quality and Access to End-of-Life Care in First Nations Communities: Policy Implications from the "Improving End-of-Life Care in First Nations Communities" Research Project.*

Appendix A

Pilot Funding Proposal

HEALTH SYSTEM IMPROVEMENT PRE-PROPOSAL (H-SIP) FORM

Section 1 – Proposal Information

Section 1 A – Pre-proposal Name and Submitting Health Service Providers

Proposal Title: Wiisokotaatiwin Program, Naotkamegwanning First Nation

Name, Address and Email of Health Service Provider(s)

Contact: Health Director Naotkamegwanning

Name: Eddie AJ White

Email: naot.healthdirector@gmail.com

Proposal CEO Approved: Chief and Council ☒ **Yes**

Section 1 B – Proposed Improvement Summary

Type of improvement being proposed (check applicable box(es)	**Does the proposed improvement require capital: (check if applicable)**
☒ Service Change (Enhancement)	☐ Renovation
☐ New service	☐ Expansion
☒ Integration activity (I acknowledge that this is not a formal request for integration, as described in the attached Glossary)	☒ Equipment investment ☒ IT investment
☐ Other (please specify)	

If the proposed improvement involves a capital project, provide a brief description of the capital project and indicate if you have submitted a capital request to the MoHLTC.

N/A

☐ Yes – Please provide date and if available the MoHLTC Capital Branch consultant assigned to your request.

☒ No

Has this pre-proposal from been submitted to other LHINs?

☐ Yes – Please indicate which LHINs:

☒ No

Section 1 C – Define the Project *(maximum 300 words)*

Wiisokotaatiwin will provide coordinated, comprehensive, person-centred and compassionate care to those who are very sick whose wish is either to remain living at home receiving home care or return home from hospital to journey in the community while supporting individual traditions beliefs and values.this program will coordinate the palliative care services of local health care providers in Naotkamegwanning including home and community care program (hccp), long term care, medical transportation, and respite care. The program includes partnerships and service agreements with regional health services such as: The First Nations Inuit Home And Community Care (FNIHCC) Program (Ontario Region), North West Community Care Access Centre (NW CCAC), Waassegiizig Nanaandawe'iyewigamig (WNHAC), Thunder Bay Regional Health Sciences Centre (TBRHSC) and Regional Cancer Centre, St. Joseph's Care Group Telemedicine Nurse, Lake Of The Woods District Hospital (LWDH), Community Health Care Professionals, Lakehead University's Centre For Education And Research On Aging & Health's (CERAH) Palliative Care Education, Lakehead University's Centre For Education And Research On Aging & Health's Improving End-Of-Life Care In First Nations Communities Project (EOLFN), Wesway, and The Kenora/Rainy River Hospice Volunteer Program. These partnerships do not duplicate existing services but provide enhanced and more integrated services that address gaps in current community capacity to support people and their families to receive palliative home care. In particular, the Wiisokotaatiwin Program will offer clients and families care and support 24/7. In the current state, there is no home care available evenings and weekends.

In the current state, all people living in Naotkamegwanning who are dying from progressive chronic or terminal illnesses (expected death) die in hospital. The FNIHCC program does not fund palliative care as an essential service element (see appendix a). While the actual number of hospital days is not known, the estimate from the local community care program is an average of 1 month of hospitalization prior to death. NW LHIN data indicate the average length of stay for a final admission leading to death is 21 days. The majority of these deaths occur in LWDH where the per diem rate is $2000/day. This means an in hospital death could cost the health care system between $42,000-$60,000 for a 3-4 week stay. These costs do not include additional hospitalization and visits to the emergency department in the last year of life.

Rationale (identify the LHINn population (health service consumers) that would benefit from the proposed service improvement, and the service or quality gap that exists now – maximum 150 words).

The LHIN population that would benefit from the proposed service are people that are living in Naotkamegwanning that have been diagnosed with a chronic or terminal illness and are in the last year of life. The majority of these individuals have advanced chronic disease and multiple co-morbidities, including diabetes and frailty. Currently, there are three to five individuals who are receiving support from the home and community care program that would meet the criteria for the Wiisokotaatiwin Program. In the current state, all these individuals would be expected to die in the hospital. Based on

available data, their projected length of stay will be 3-4 weeks prior to death. These clients would benefit by receiving palliative care assessments in the community, enhanced home care services, and improved access to palliative care specialist's, consultations and family education and support (hospice volunteer visiting, respite care.)

Benefit to the community (briefly describe how this proposed improvement will improve the health care system and/or health status of the community e.g. Health outcomes, access to health services, quality of care, coordination of services, patient's choice, uptake of best practice – maximum 150 words).

A needs assessment conducted in Naotkamegwanning in 2012 indicated that if services were available and adequate the majority of community members would prefer to die at home. Recommendations included:

-Increased funding and community resources that allow for 24 hour, 7 day a week home care provision, and greater support for family caregivers
-Advocating for improved communication and collaboration between external health care providers and institutions and Naotkamegwanning health care providers to improve continuity of care and discharge planning
-Formalized partnerships between internal and external health care organizations to support, enhance and build local capacity for providing palliative care services
-Advocating for external health organizations to collect data about palliative care service use by residents to assist with health service planning and evaluation
-Provide education to local health care providers about palliative and end-of-life care
-Provide education to external health care providers to improve the cultural safety of care

The proposed Wiisokotaatiwin program will give people with advance chronic or terminal illness the choice to receive palliative care in their home. Clients will receive a comprehensive palliative care assessment and participate in a case conference with care providers to develop a coordinated, individualized care plan in the comfort and security of their own home. Expert consultation will be available to them. Additional after hours nursing and PSW support will prevent unnecessary ED visits and reduce transportation issues to access care in Kenora. Community members will receive culturally safe and relevant care in their home. Being able to receive palliative care at home enhances the opportunity to meet the individuals' psychological, emotional, and spiritual needs within the context of their family, community, and culture. The program will also provide families with informational and emotional support in their caregiving role and respite care. The addition of evening and weekend home care services and respite care services will reduce the cost and stress of residents needing to access care outside the community, primarily in Kenora.

Collaboration (Briefly describe your partnerships and how the collaborating HSPs will work together, (in general terms) to implement the proposed improvement – *maximum 150 words*).

Ove the last year, three workshops have been held involving 24 internal and external health care providers for purposes of "journey mapping" the experience of people from Naotkamegwanning who require palliative care and wish to receive their care at home. These workshops have identified who the key partners are, what services are currently provided, gaps in service, and the needed service enhancements. The current and future state of palliative care service provision in Naotkamegwanning has been mapped out. This proposal is the outcome of these workshops.

The collaborators are Naotkamegwanning Home and Community Care/LTC, FNIHB, NW CCAC, WNHAC, TBRHSC and Regional Care Centre, St. Joseph's Care Group Telemedicine Nurse, LWDH, Community Health Care Professionals, CERAH Palliative Care Education, CERAH EOLFN project, Wesway, and the Kenora/Rainy River Hospice Volunteer program. These collaborators are committed to working together to achieve the objective of supporting clients from Naotkamegwanning to die at home if that is their wish.

Health System Sustainability (Briefly identify how this proposed improvement will result in efficiencies to the health care system and/or your organization, e.g. reduced duplication of services, new model of care, reduce length of stay, reduce readmissions, demonstrated cost benefit, collaborative budgeting, reinvestment of existing resources – maximum 150 words)

This is an enhanced model of care which is aligned with the NW LHIN's population based goal to improve the health status and care experience for individuals living in North Western Ontario with a focus on the First Nations population. Currently all residents of Naotkamegwanning receive their end-of-life care in LWDH at an estimated cost of $42,000-$60,000 per person, assuming 21-30 days of hospitalization at $2000/day. Data are not available on the actual number of hospital days and emergency department visits in the last year of life, however, they are perceived by Naotkamegwanning Home and Community Care providers to be frequent and avoidable if services were available within the community.

The model addresses the gap for palliative home care services in First Nations communities. The model has potential to reduce hospital length of stay at end of life, reduce hospital admissions and ED visits in the last year of life, improve client and family satisfaction, improve health care provider's satisfaction and increase collaboration between primary care providers internal and external to the First Nation. A unique feature is the enhanced collaboration between federally and provincially funded health care services. There will be no duplication in services. Home care costs for palliative care services are much less than hospital costs.

Alignment with Integrated Health Service Plan (IHSP) (Please identify which of the LHIN IHSP priorities relate to this proposed improvement and explain how they are connected - *maximum 150 words)*

Almost 20% of the NW LHIN's population is Aboriginal, many living in more than 60 First Nations communities. This pilot project will contribute to the development of an integrated regional palliative care program by creating a model of care that is transferable from Naotkamegwanning throughout the district and province.

The Wiisokotaatiwin program directly aligns with all four of the NW LHIN IHSP priorities.

Building an integrated health care system: The program will improve access to palliative care by increasing collaboration between primary care providers and improving communication between local stakeholders and the primary care providers. The Naotkamegwanning Home and Community Care/LTC, FNIHB, NW CCAC, WNHAC, TBRHSC and Regional Care Centre, St. Joseph's Care Group Telemedicine Nurse, LWDH, Community Health Care Professionals, CERAH Palliative Care Education, CERAH EOLFN project, Wesway, Kenora/Rainy River Hospice Volunteers have all agreed to partner in this pilot. This new model provides a community based alternative to receive palliative and EOL services in the community. This collaboration between the primary care providers and local stakeholder's goal is to improve transition between care settings, improve coordinated post discharge support for the client and to provide access to community based palliative care assessments and enhance palliative home care.

Building an integrated eHealth Framework: Naotkamegwanning is a rural community without the infrastructure or training to support advances in eHealth. The pilot is collaborating with partners to bridge this gap through the use of telemedicine and tablet which are innovative eHealth technologies.

Improving access to care: The pilot is collaborating across sectors with health care providers to improve identification, assessment, and care planning for clients in need of palliative care services. These clients can be in the acute care setting or in the community of Naotkamegwanning.

Enhancing chronic disease prevention and management: All clients with the Wiisokotaatiwin program are living and managing with one or more chronic diseases. The program is providing enhanced nursing, PSW, Homemaking and respite services in order to support individuals to stay in their home and community. These individuals will have the option to stay at home to the end of life if they choose.

Pre-proposals that do not align with the LHIN's IHSP (Please identify why this proposed improvement should be a priority to the local health of the community - *maximum 150 words*).
N/A

Section 2 – Health Service Provider Partners

Identify HSPs that you collaborated with in developing this pre-proposal and identify those that have agreed to actively collaborate/partner on the proposed improvement.

Organization	Contact Information	Nature and objective of the Collaboration
First Nations Inuit Health Branch, Ontario Region (Health Canada)	Edey Hobson, Nurse Advisor, First Nations and Inuit Home and Community Care (FNIHCC) Program	Coordination of FNIHCC with NW CCAC services, project advisor Provide assistance to HCC Coordinator with documenting palliative care service provision using the existing FNIHCC electronic Service Delivery Reporting Template (eSDRT) Assist with data analysis and interpretation of (eSDRT) to provide quantitative information about program functioning and client utilization of services Assist with review of Loan Cupboard contents to ensure appropriate equipment and supplies available for palliative care clients Collaborate with NW CCAC on the development of an information sharing protocol with HCC programs Assist with the development of service delivery plans related to palliative care Assist with establishing linkages with other services and programs Facilitate communication with other federally administered programs, e.g. Non Insured Health Benefits
NW CCAC	Tuija Puiras CEO; Kathryn Hughes Director	Coordination of NW CCAC with FNIHCC services, project advisor Assist pilot with case conferencing/assessment of PC client needs at LWDH and in Naotkamegwanning Assess eligibility of clients for CCAC services and provide services required For evaluation, assist pilot with quantifying and costing service provision for palliative home care provided on Naotkamegwanning Accept palliative care referrals for nursing from the physician or NP for clients in Naotkamegwanning Accepts referrals from the HCC for PSW, OT, PT, SW Share equipment catalogue with pilot as a resource for palliative clients receiving home care

		Collaborate with FNIHB on the development of an information sharing protocol with HCC program
Waasegiizhig Nanaandawe' Iyewigamig, Kenora Ontario	Anita Cameron, ED	Provision of palliative care assessment and services, project advisor NP goes to community twice a week (currently going once a week due to staff shortage): Assist with identification and assessment of clients for program Conduct home visits for palliative clients as requested by HCC (see budget $350/month) Provide monthly PPS for clients in program and weekly PPS if client is EOL. Can provide client consultation via telemedicine tablet once in use Provide staff opportunity for palliative care education e.g. LEAP offered in Kenora in March 2015 Health Promotion Team will organize community palliative care awareness sessions
Thunder Bay Regional Health Sciences Centre	Trina Diner, Manager of Palliative Care and Telemedicine	Collaboration on telemedicine project; First Nations community awareness sessions, facilitate hospital discharge planning Collaborate to provide HCC access to telemedicine licence and use of tablet Facilitate discharge planning with TBRHSC and First Nations communities
St. Joseph's Care Group	Robin Cano, Telemedicine Nurse, Hospice Palliative Care	Collaboration of telemedicine community palliative care consultations Assist/provide PC consultations via OTN and tablet Assist HCC Coordinator with client care planning Train HCC Coordinator in the use of the tablet and OTN Hospice Program can be called after hours by those involved in care if there is a need for specialty consultation Interdisciplinary hospice team can be accessed by telemedicine for consultation and assessment.
Lake of the Woods District	Kathy Dawe, VP Patient	Collaboration to improve discharge planning protocol with Naotkamegwanning Home and Community Care, improve access to palliative care assessments, assist

Hospital, Kenora, Ontario	Services/Chief Nursing Officer	HCC to develop cultural competency training for external home care providers, improve patient navigation for HCC clients from Naotkamegwanning Provide Acute care services that are culturally safe and relevant Identify clients benefitting from PC approach D/C plan that includes HCC Coordinator- enhance communication and early d/c planning Every effort will be made not to discharge patients on a Friday unless HCC services have been organized (measure indicator) Phone consultation with palliative care nurse as needed for pain and symptom management OTN used for family visits and client consultation as needed Promote physician awareness of the Wiisokotaatiwin program in hospital and emergency department and promote their engagement in the pilot
Community Health Care Professionals	Vicki Barnes, Owner/Manager	Enhanced provision of palliative nursing services in Naotkamegwanning Provide PC assessments in the community Facilitate and participate in PC case conferences Provide an on-call nursing service (consultation and visit if required) for evening and weekends as required (see budget) Provide and promote opportunities for staff to take PC education e.g LEAP (see budget)
CERAH EOLFN Project	Mary Lou Kelley, Holly Prince	Pilot project facilitation Provide facilitation of pilot project (facilitate partnerships, facilitate management committee activities, assist with managing the budget as requested by AJ White, facilitate data collection) Assist with evaluation of pilot Provide final report for pilot project
CERAH Palliative Care Education Initiative	Stephanie Hendrickson	Organize LEAP course in Kenora in February/March 2015 Provide PC education to HCC staff and external health care providers.

		Service providers from Naotkamegwanning, CCAC, WNHAC, LWDH and Community Health Care Professionals will participate (tuition will be subsidized as required - see budget)

Section 3 – Accountability, Service Details, Financial Impact & Implementation Timelines

Section 3 A – Accountability. Please describe in detail how you would:
demonstrate the value of the project both in the short term and long-term *(This should include any narrative successes that are not clearly measurable, proof that the public would see this project as good value for money/value to the system, etc.)*

The pilot project will be managed by a committee chaired by Maxine Ranville, HCC Coordinator. Membership includes: AJ White, Health Director; Melanie Copenace, Band Councillor/Health Portfolio; Holly Prince and Mary Lou Kelley, CERAH EOLFN. The management committee will meet monthly by telephone to monitor activities, solve problems and to ensure that the goals of the project are being met.

Clients and internal and external health care providers will agree that the following objectives have been met by the pilot:

- Clients have the choice to receive palliative care at home
- Clients receive quality palliative home care in Naotkamegwanning
- Families are more educated and supported in their role as caregivers
- Local health care providers are more competent and confident in the delivery of palliative care
- External health care providers provide more culturally relevant care
- Health system organization and care processes are improved to provide palliative home care in Naotkamegwanning
- Residents of Naotkamegwanning have improved access to palliative care
- Clinical information sharing among health service provider agencies has improved
- Improved accessibility of health care using technology i.e. OTN and tablet
- Better communication and continuity of care between primary care and palliative care specialists
- Fewer unnecessary ED visits, fewer avoidable admissions to hospital
- Increased adoption of best practices for palliative care
- System integration is improved to utilize resources more efficiently
- Naotkamegwanning Model of Care is transferable to other First Nations communities

Measure accountability and success of the project both in the short-term and long-term (*This should include clearly defined project performance indicators including comparisons with historical performance, benchmarks for similar services, and performance targets with rationale. Consider inclusion of system level impacts (e.g. % of ALC days, decrease in (re)admissions to hospital, decrease in LTC waitlist), improvements in client satisfaction, increase in efficiency of service delivery, etc.*)

Level	Baseline	Predicted Outcome
Program Level More residents in Naotkamegwanning receive palliative services at home for advanced chronic disease and end of life	0	5 clients by end of pilot March 31, 2015
Clients receive a palliative care assessment in community when identified	0	5+ clients assessed in community by end of pilot
Palliative Care Case Conferences are held that include local and external health care providers with pilot partners (NW CCAC, LWDH, WHNAC, TBRHSC)	0	5+ Integrated service delivery (LWDH, NW CCAC, WHNAC and HCC)
Integrated care plan is developed and implemented. Track clients by CHA scores/amount of service based on PPS/frequency of service	0	5+
Cost of having a palliative care nurse on-call for evening and weekends as required. Track Number of hours of service and type of service and time of day	unknown	$ value known
Cost of palliative care nursing services is known (days, evenings, nights, weekends) Track Number of hours of service and type of service	unknown	$ value known
Cost of PSW and homemaker services is known (days, evenings, nights, weekends) Track number of hours of PSW and type of work and time of day	unknown	$ value known
Cost of Respite Care services is known (days, evenings, nights, weekends) Track number of hours of PSW and type of work and time of day	unknown	$ value known

Cost of Professional services to support palliative home care is known (PT/SW/OT etc.) (days, evenings, nights, weekends) Track number of visits and reason for referral	unknown	$ value known
Cost of medications (oxygen) and equipment/supplies to support palliative home care is known	unknown	$ value known
Cost of client/family transportation related to PC is known	unknown	$ value known
Hours of Wiisokotaatiwin program coordination is known	Unknown	# of hours known
HCC attendance at PC case conference	0	5+
HCC attendance at PC/EOL discharge planning	0	5+
Education for direct care providers	6 PSW have received PC for Front Line Workers	1 HCC provider to complete LEAP 6 External HCC to complete LEAP (Kenora March 2015) 1 HCC provider trained to use Inter-Rai CHA
Clients who would benefit by palliative care are identified earlier in their journey by Home and Community Care Program (prior to 50% on the PPS)	3 clients identified as eligible for Wiisokotaatiwin	5+ clients on the program
HCC consultation with PC experts	0	10+
System Level Wiisokotaatiwin Program	No palliative care program description relevant to First Nations Communities	Description of program model disseminated to other First Nations communities
The number of hospital days for client in the last year of life (registered with Wiisokotaatiwin) including reason for admission.	Unknown (average EOL admission in Kenora/Rainy River is 21 days)	# of hospital days known

The number of ED visits by clients in the last year of life (registered with Wiisokotaatiwin) Track reason for visit	Unknown	# of ED visits known
Discharges from hospital are planned collaboratively with HCC	0	10
Fewer Hospital Deaths	5 in 2014 for eight months	2 in 2014 for 7 month period (September 1 – March 31, 2015)
HCC health care providers receive palliative care education	6	10
External health care providers receive palliative care education (LEAP)	0	6

Section 3 B – Service Details

Service/Volume Details	
Proposed Service Change (Volume/Outcome)	Provide Details i.e. additional number of visits, services provided or residents (clients) served by type of service,
☐ No Change	
☒ Increase	Increase access to palliative home care services and support services in Naotkamegwanning. Palliative care education for family, internal, and external health service providers will increase local capacity of PC knowledge and skills to provide local palliative care services. Use of OTN equipment will increase access to PC consultation with interprofessional health care providers, and address gaps of access to specialized health services. Increase client satisfaction by receiving care in setting of client's choice and supporting client access to cultural, spiritual, and language needs
☒ Decrease	Decrease hospitalization and hospital deaths. Decrease number of hospital days in last year of life.

Section 3 C – Financial Details

Financial Details			
	Provide Details	$ One-time	$ Base
☐ No new funding required			

☐ Savings Identified			
☐ One time project funding (ongoing funding not required)			
☒ Start-up funding	☒ Consultation/training/ evaluation ☒ Staff ☒ Other (specify) equipment	$7000 $19,000 $4000	
☐ Ongoing operating (out-year funding)	☐ Staffing ☐ Supplies ☐ Other (specify)		
☐ Capital			
☒ Other funding sources	Improving End-of-Life Care in First Nations Communities Research Project	In kind project facilitation (0.5day/week= $4145/7mths)	In Kind Community Facilitator, Admin Assistance $37,452/7 months

Section 3 D – Implementation Timelines. Please provide estimated timelines for project development and implementation

Project to run September 1, 2014 - March 31, 2015

I acknowledge that this submission is not formal notice of a proposed integration to the LHIN as contemplated by s. 27 of the Local *Health System Integration Act, 2006* ("LHSIA"). HSPs wishing to provide notice to the LHIN of a proposed integration under s. 27 of LHSIA, should contact the LHIN for more information.

Signature: _____

Name: _____

Title: _____

Date: _____

First Nations and Inuit Home and Community Care (FNIHCC) Program
Program Description and Capacity to Support Wiisokotatawin Program

Program Description[iv]

The First Nations and Inuit Home and Community Care (FNIHCC) Program will provide basic home and community care services that are: comprehensive, culturally sensitive, accessible, effective and equitable to that of other Canadians and responsive to the unique health and social needs of First Nations and Inuit.

The program is comprised of essential service elements and may be expanded to include supportive service elements, provided the essential service elements are met. When communities already have all essential services through alternate sources, the program will not duplicate these services, but will allow communities to augment, through supportive service components, the current services.

The program will coordinate and link with existing programs and services at the community and/or provincial/territorial level.

Eligible Recipients

The eligible recipients for this program are:

- First Nations and Inuit of any age; and
- Who live on reserve, Inuit settlement or First Nations community North of 60; and
- Who have undergone a formal assessment of their continuing care service needs and have been assessed to require one or more of the essential services; and
- Who have access to services which can be provided with reasonable safety to the client and caregiver, within established standards, policies and regulations for service practice

Essential service elements include[v]**:**

- A **structured client assessment process** that includes on-going reassessments and determines client needs and service allocation
- A **managed care process** that incorporates case management, referrals and service linkages to existing services provided both on and off reserve/settlement
- **Home care nursing services** that include direct service delivery as well as supervision and teaching of personne providing personal care services
- Delivery of **home support services** (personal care and home management)

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[iv] Adapted from: Program Criteria, FNIHCC Planning Resource Kit, FNIHB, Health Canada (2000)
[v] Adapted from: Summative Evaluation of the FNIHCC, Health Canada (2007/2008)

- Provision of **in-home respite care**
- **Established linkages** with other professional and social services
- Provision of and access to specialized **medical equipment, supplies** and specialized pharmaceuticals
- The capacity to **manage** the delivery of the home and community care program
- A system of **record keeping and data collection** to carry out program monitoring, ongoing planning, reporting and evaluation activities

Supportive service elements may include (examples)[vi]:

- Home-based palliative care services
- Facilitation and linkages for rehabilitation and therapy services
- Adult day programs
- Meal programs
- Mental health home-based services for long-term psychiatric clients and clients experiencing mental or emotional illness
- Traditional counseling and healing services
- Social services directly related to continuing care issues

Capacity to Support Wiisokotatawin Program

As detailed in the Program Description, home-based palliative care services may be offered as a supportive service element through the Naotkamegwanning Home and Community Care Program (HCCP) provided that essential service elements are being met. Regarding funding, this does not change the funding amount Naotkamegwanning receives from First Nations Inuit Health Branch to deliver their HCCP. Should the program wish to offer supportive services to meet a determined community need, this must be done within the existing budget and not affect the delivery of the essential service elements.

Working with the Wiisokotatawin Program, the Naotkamegwanning HCCP could facilitate the following services for palliative care clients:

- Provision of any of the essential service elements (based on the structured client assessment and care plan)
- Palliative care specific services as supportive service elements (enhanced essential services and palliative specific services as described by the Wiisokotatawin Program)

[vi] Adapted from: Program Criteria, FNIHCC Planning Resource Kit, FNIHB, Health Canada (2000)

Appendix B

Weekly Tracking Sheets

Wiisokotaatiwin Weekly Service Report

This form is for tracking the weekly (Mon–Sun) service provision for Wiisokotaatiwin clients.

Please complete this form for <u>each Wiisokotaatiwin client</u> every Monday.

I. Demographic Information

Client ID: _____
Week of: _____
Completed By: _____

II. Services Provided

Using the table below, please indicate and describe all services provided to the client in the past week (Mon – Sun).

Service provided in past week (Mon – Sun)	**Day &Time service was provided**	**Service Provider**	**Location of service delivery** (home, clinic, etc.)	**Method of service delivery**	**# of hours**	**Comments**
Direct Client Services						
Home nursing care Type of service:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Home support – PSW Type of service:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Home support – homemaker Type of service:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30			☐ face-to-face ☐ telephone ☐ telemedicine		

Service provided in past week (Mon – Sun)	**Day &Time service was provided**	**Service Provider**	**Location of service delivery** (home, clinic, etc.)	**Method of service delivery**	**# of hours**	**Comments**
	☐ after hours			☐ other: specify_____		
In-home respite: Type of service:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Traditional Healing	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Medication review	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Medical Transportation	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Counselling / support with family	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Counselling / support with client	Weekday ☐ 8:30-4:30 ☐ after hours			☐ face-to-face		

Service provided in past week (Mon – Sun)	**Day &Time service was provided**	**Service Provider**	**Location of service delivery** (home, clinic, etc.)	**Method of service delivery**	**# of hours**	**Comments**
	Weekend ☐ 8:30-4:30 ☐ after hours			☐ telephone ☐ telemedicine ☐ other: specify_____		
Family / client education	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other (e.g., second respite or PSW service)	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other (e.g., second respite or PSW service)	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other (e.g., third respite or PSW service)	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Case Management						
Client palliative care assessment / reassessment	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30	i.e., Who participated?		☐ face-to-face ☐ telephone ☐ telemedicine		

Service provided in past week (Mon – Sun)	**Day &Time service was provided**	**Service Provider**	**Location of service delivery** (home, clinic, etc.)	**Method of service delivery**	**# of hours**	**Comments**
	☐ after hours			☐ other: specify_____		
Care coordination / scheduling appointments	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Getting medical supplies & equipment Specify:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Getting pharmaceutical supplies Specify:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Referrals & linkages Specify:	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Record keeping & data collection	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other	Weekday ☐ 8:30-4:30 ☐ after hours			☐ face-to-face		

Service provided in past week (Mon – Sun)	**Day &Time service was provided**	**Service Provider**	**Location of service delivery** (home, clinic, etc.)	**Method of service delivery**	**# of hours**	**Comments**
	Weekend ☐ 8:30-4:30 ☐ after hours			☐ telephone ☐ telemedicine ☐ other: specify_____		
Other	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other						
Crisis intervention Specify: Do you think this avoided a hospital visit?	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
HCC Staff mentoring / clinical education by Coordinator	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
HCC Coordinator seeks clinical	Weekday ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone		

Service provided in past week (Mon – Sun)	**Day &Time service was provided**	**Service Provider**	**Location of service delivery** (home, clinic, etc.)	**Method of service delivery**	**# of hours**	**Comments**
consultation about PC	Weekend ☐ 8:30-4:30 ☐ after hours			☐ telemedicine ☐ other: specify_____		
Other (Specify)	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		
Other (Specify)	Weekday ☐ 8:30-4:30 ☐ after hours Weekend ☐ 8:30-4:30 ☐ after hours			☐ face-to-face ☐ telephone ☐ telemedicine ☐ other: specify_____		

III. Unmet needs

Did the client have any unmet needs this week?

☐ No

☐ Yes → Explain:_____

_____

_____

IV. Hospitalization Admissions & ED Visits

	Date/Time	Reason	Do you think this could have been avoided?
Hospital Admission			☐ Yes ☐ No Explain:
Emergency Department Visit			

* Hospital Discharge Information

1. Was the client discharged from hospital in the past week?

   ☐ No ☐ Yes

   a. What was the total length of stay (days)? _____
   b. Did any EOL/PC discharge planning take place? ☐ Yes ☐ No
   c. Was the discharge planned collaboratively with HCC? ☐ Yes ☐ No

V. Case Manager Information and Support Seeking

1. In your role as case manager, did you need any consultation regarding this client this week?

☐ No

☐ Yes → Who did you consult with?

2. Did you have to get approval to pay for any client services, equipment, pharmaceuticals, etc. beyond what is already covered by home and community care or non-insured health benefits?

☐ No

☐ Yes → Specify & Explain:

3. Please specify/describe anything else that you did in relation to the client this week (that isn't already captured on this form).