

A loon is shown in profile, facing right, with its head tilted back and its long, pointed beak pointing towards the top right corner. Its wings are spread, showing a pattern of dark and light feathers. The bird is in the water, with ripples visible around its body. The background is a deep blue, slightly textured water surface.

# Palliative Care for Vulnerable and Underserved Populations

Needs Assessment Report

May 15, 2018



Anishinabek Family Care



Ontario

North West Local Health  
Integration Network





Dilico

Anishinabek Family Care

*Funding for this project provided by the North West  
Local Health Integration Network (LHIN)*



# Palliative Care for Vulnerable and Underserved Populations

## Needs Assessment Report



*I was once homeless, being homeless does not define the human you are or the qualities you have, it just means you are not sleeping in a house/ apartment tonight. It means you struggle with the most basic of things that most humans take for granted. I am not perfect and have moments of judgement, although I, at the end of the day, review and hope to be better the next.*

- Service Provider



## Table Of Contents

EXECUTIVE SUMMARY .....	05
DEFINITIONS .....	14
INTRODUCTION .....	15
PURPOSE OF THE SURVEY .....	16
THE APPROACH .....	17
ENVIRONMENTAL SCAN .....	18
Target Population Characteristics .....	18
Palliative Care Providers And Regional Resources .....	19
Current Programs, Resources, And Research .....	19
Promising Programs & Possible Opportunities .....	20
SURVEY RESULTS SUMMARY .....	22
Service User Survey Results .....	23
Demographic Information .....	23
Health Related Questions .....	25
Service Provider Survey Results .....	31
Demographic Information .....	31
Palliative Care Information From Service Providers .....	32
Coffee Talk Information Exchange .....	37
A NEEDS ASSESSMENT REPORT: RECOMMENDATIONS AND NEXT STEPS .....	38
LIMITATIONS .....	40
CONCLUSION .....	40
REFERENCES .....	41
APPENDICES .....	44

This report was respectfully written on the treaty territory of the 1850 Robinson Superior Treaty, Treaty 3, Treaty 5, Treaty 9, and on the traditional lands of the Fort William First Nation.

Dilico Anishinabek Family Care carried out the Innovative Models of Community Palliative Care for Vulnerable and Underserved Populations Project Report with funding provided by the North West Local Health Integration Network and support and contributions from the following organizations:

- Centre for Education and Research on Aging & Health, Lakehead University
- Lakehead University
- Norwest Community Health Centres
- North West Local Health Integration Network
- Regional Indigenous Cancer Program
- Regional Cancer Care Centre
- North West LHIN Regional Palliative Care Program
- Thunder Bay Regional Health Sciences Centre
- Hospice Northwest
- Thunder Bay Regional Health Science Centre, Palliative Care Physicians
- Thunder Bay Shelter House
- Wequedong Lodge
- Sioux Lookout Meno Ya Win Health Centre, William A. “Bill” George Extended Care Facility



*Find a way to get people home with the services they need at home, lots of friends have died at the hospital and would have rather been at home.*

*- Service User*



# Executive Summary

## Project Summary

Poverty and homelessness are growing socio-economic issues experienced on both local and national levels. Homeless and vulnerable populations living with life limiting/threatening and terminal illnesses often are identified late and die early without access to high quality palliative care (Cipkar & Dosani, 2016). There is stigma, discrimination, racialization, and trauma known to be associated with the provision of care for this population from social/health institutions (Cipkar & Dosani, 2016). These practices create significant barriers to palliative care identification and access to quality end-of-life care for those who are homeless or vulnerable. The purpose of this report is to explore current practices and best approaches for delivering palliative and end-of-life care services to people who are vulnerable and live homeless in Northwestern Ontario.

## Process

Dilico Anishinabek Family Care identified a project lead to coordinate and direct this initiative. A Partnership Advisory Team was established to provide advice on the project scope and approach which resulted in an integrated knowledge translation strategy with regular communication built into the work plan. The project involved a six-step plan including: Identifying and Engaging Stakeholders, Defining Target Population, Collecting and Analyzing Data, Validating and Prioritizing Findings, Documentation and Communication, and a Final Report and Recommendations.

The collection of data involved conducting surveys for service users and service providers that were completed either independently (service providers) or through an interview format (service users) with some distribution assistance from linkages established with community organizations.

## Findings

The majority of service users surveyed identified as Indigenous and many did not have stable housing as most reported their place of residence as emergency shelters. Many service users did not report having a primary health care provider and they tended to use the emergency room or walk-in-clinics when they were sick. Community was identified as an important factor and resource for transportation and social support. Holistic treatment and traditional healing was also identified as important to service users.

Most of the service providers identified offering palliative care services in their workplace, yet over half of the group surveyed reported not having received any formal training related to palliative care. Service providers expressed that everyone has a right to receive and access care and clients deserve to be treated with understanding, trust, compassion, respect, an open-mind, with dignity, and without judgement.

Both service users and service providers reported the importance and necessity of palliative care services, but several barriers and gaps were noted by both groups that currently interfere with provision of these services for the vulnerable population. Some of the issues, barriers and areas of concern that were noted by both service users and service providers involved lack of seeking treatment by the vulnerable population, difficult/discriminatory admission criteria, lack of knowledge concerning palliative services available to this population, a need for care providers and more accessible services especially within remote communities, and the need for additional educational resources.

# Recommendations for Further Actions

The broad recommendations included: continued collaboration, funding and resources, increase access, eliminating discriminatory beliefs, education for service providers, education for service users and housing first. These broad recommendations were further narrowed down into itemized recommendations for specific organizations, services and programs, such as the Centre for Education and Research on Aging & Health, the North West Local Health Integration Network, the North West Local Health Integration Network Regional Palliative Care Program, and Health and Social Service Providers. Recommendations and next steps were developed based upon the survey results as well as the consideration of current services, resources and unique geographical composition of the North West Local Health Integration Network region and are as follows and are not listed in priority;



## Continued Collaboration

It is imperative to develop and maintain a sustainable coordinated continuum of care to address holistic needs, traditional healing, and increase communication between health providers and social services, which will create opportunities to develop programs and services collectively. This can be accomplished through nurturing and maintaining an inclusive collaborative working relationship among stakeholders at every level.

Recommendations include:

- North West LHIN and Sub-Region Planning Tables:
  - Create a means of communication and collaboration between health and social services providers to increase capacity and services for the target population.
    - Support the Regional Palliative Care Program (RCPC) to establish a working group to develop a more detailed plan/proposal to support the implementation of this report's recommendations.
    - Identify organizations and health care providers that will champion and identify the implementation priorities.
    - Ensure that individuals with lived experience of homelessness (service users) are meaningfully engaged in the development of further recommendations and any new programs and services targeted to them.
- Sub-Region Planning Tables review and incorporate this report's recommendations into their planning.



## Funding and Resources

Advocate for increase in funding and resources directed toward developing integrated and organized services for the target population. The need for funding and resources was prominent throughout this survey. More funding is necessary to ensure the resources available can reach those in need and to ensure that the services and staff providing services are of the best quality possible.

Recommendations include:

- North West LHIN RPCP and its partners:
  - Include a mechanism to access services for homeless and vulnerably housed individuals in the development of an Integrated Palliative Care Clinical Program while recognizing that this is a unique population that requires special attention and resources.
  - Complete an inventory of organizations currently providing services to the homeless and vulnerably housed population in each sub-LHIN region.
- North West LHIN and North West LHIN RPCP:
  - Work with partners who provide lodging to explore the feasibility of creating community-based hospice-like spaces that would support the homeless and vulnerably housed at the end-of-life, both in the City of Thunder Bay and other LHIN Sub-regions.
- North West LHIN:
  - Fund dedicated health service delivery within social service organizations like emergency shelters and managed alcohol programs that are providing palliative care to homeless individuals who are dying.





## Increase Access

Services need to be more easily available. Where services do exist, they are often not readily available to those without a fixed address and those without a health card or primary health care provider. As well, those located in remote communities have additional challenges to overcome when attempting to access services. It is also necessary to use current demographic data to prioritize the need for culturally appropriate and inclusive care. Adjustments are needed to allow this population access to services when required.

Recommendations include:

- North West LHIN:
  - Request that Health Service Providers track and report on the number of referrals received for individuals who have no fixed address, no Health Card, and/or no phone number. Report on the outcome of these referrals (e.g. was intake/assessment completed, were services provided, was referring provider informed of referral outcome?).
- North West LHIN Home & Community Care:
  - Work with contracted service providers and other partners to develop a strategy to deliver home care services to individuals with no fixed address and/or no phone number.
  - Dedicate and develop services for people who live homeless, vulnerably housed and are marginalized.
  - Support access to all end-of-life care options, which includes palliative care and medical assistance in dying.
- Health and Social Service Providers:
  - Identify, examine, and address organizational barriers (e.g. policies & procedures, location/transportation, physical environment) that may prevent homeless and vulnerably housed individuals from accessing services.
- Ministry of Health & Long Term Care & Indigenous & Northern Affairs Canada:
  - Collaboration between both levels of government to ensure equitable access to all government funded services whether on or off reserve.



## Eliminating Discriminatory Beliefs and Practices

Initiatives to address stigma are required in supporting the interface between service providers and service users. Stigma towards those who are homeless or vulnerably housed, specifically those challenged with addictions and related issues, was a topic that was frequently raised by both service users and providers. These changes begin with governmental agencies that determine who can receive services, following through to service providers who require a greater understanding of the issues facing this population, and to the public. Where possible, evidence-based approaches should be prioritized over approaches where evidence is preliminary, or lacking.

Recommendations and next steps include:

- North West LHIN RPCP and its partners:
  - Identify natural leaders within the homeless community in Thunder Bay and the region who could be recruited to assist with 1) the education of providers, and 2) engagement of the target population. A next step would involve expanding this pilot initiative to other communities.
- North West LHIN, North West LHIN RPCP, and Health and Social Service Providers:
  - Provide education to all staff on the lived experiences of the homeless and vulnerably housed and their challenges in accessing care.
  - Continue to support completion of recognized cultural safety training for service providers (e.g. San'yas Indigenous Cultural Safety).
  - Evaluate the need for ongoing cultural competence education and training within the North West LHIN region.



## Education for Service Providers

Health and social service providers could benefit from additional training in palliative care, advanced chronic disease, vulnerably housed and homeless populations, and Indigenous populations. Healthcare providers require an understanding of the unique issues these populations face when accessing care. Additionally, healthcare and social service providers could benefit from training on the types of services that are available to whom, and how these services can be accessed.

Recommendations and next steps include:

- Centre for Education and Research on Aging & Health (CERAH):
  - Plan a Lunch & Learn series on palliative care for homeless and vulnerably housed populations.
  - Increase awareness of palliative care education opportunities for service providers.
  - Identify and inventory existing palliative care education programs for service providers working with the target population.
  - Investigate evidence based practices in regards to competence education concerning the target population.
- North West LHIN:
  - Support the development of education relating to the target population in consultation and collaboration with those who have lived experience.





## Education for Service Users

Providing educational opportunities for the service user population is beneficial. The general sense emerging from service users was a lack of awareness of palliative care and the types of services that were available to them. This information should be readily available and easily accessible to service users so that they are able to find services when necessary. Using novel knowledge translation and dissemination approaches (e.g., health services survival guide) which actively engages those most likely to benefit from services will be important.

Recommendations include:

- North West LHIN RPCP and its partners:
  - Explore the feasibility of organizing a forum/conference for service users delivered by service users.
  - Identify natural leaders & helpers within the homeless community in Thunder Bay who could be recruited to assist with 1) the education of other service users, and 2) provide peer mentorship and support (i.e. model developed by the Champlain LHIN).
  - Determine key sites to disseminate information on available resources to the target population.
  - Ensure there is a plan for suggested strategies above.



## Housing First

Is an agreed approach that offers permanent, affordable housing as quickly as possible for individuals and families experiencing homelessness and in addition provides supportive services and connections to the community based-supports needed to retain housing.

Recommendations include:

- North West LHIN:
  - Adopt a housing first model.
- Regional and City District Social Services Board and /Ontario Aboriginal Housing:
  - Review and improve access to subsidized housing for service users identified with palliative care needs.

# Definitions

## Chronic Disease:

Can be defined as persisting illness or ailment that tends to begin and develop gradually over a prolonged period of time, can be life limiting, has a variety of causes and treatment options, and can adversely impact one's quality of life (Department of Health and Community Services, 2018).

## Life Limiting Illness:

Is defined as having an incurable medical condition or disease that results in the shortening of a person's life span, or the expectation of premature death (Oxford University Press, 2018; St. Clare Hospice, n.d.).

## Life Threatening Illness:

Is defined as having a medical condition that may or may not respond to treatment resulting in the possibility of cure or remission, such as cancer (Boyden, Curley, Deatrick, & Ersek, 2018)

## Homelessness:

A simple definition would be the absence of a permanent or fixed address or home, but homelessness is actually more complex and can be experienced along a continuum that can include being unsheltered (absolutely without a home), emergency sheltered (sleeping in places or at organizations that offer short term or overnight accommodations), provisionally accommodated (having a temporary living space or place with no guaranteed permanence), and at risk of homelessness (people having a home but are at risk of losing it due to lack of affordability, or unsafe housing concerns) (Kauppi, O'Grady, Schiff, Martin, & Ontario Municipal Social Services Association, 2017).

## Indigenous Peoples:

Indigenous Peoples include Aboriginal Peoples who are the original inhabitants of Canada, and the Constitution Act, 1982 Section 35(1) protects Aboriginal and treaty rights and recognizes that Aboriginal people include Indian, Inuit and Metis peoples of Canada (Constitution Act, 1982, s35 (1)(2)). First Nations, Inuit and Metis peoples are not a cultural group to Canada, but rather, distinct constitutionally recognized peoples with Aboriginal and treaty rights.

## Indigenous Homelessness:

A human experience lived through or described in the worldviews of First Nations, Métis, and Inuit communities, families, and individuals who are without or cannot immediately acquire appropriate (safe, affordable, and permanent) housing, and are "isolated from their relationships to land, water, place, family, kin, each other, animals, cultures, languages and identities" (Thistle, 2017).

## Invisible/Hidden Homelessness:

Is the state of being without a home but not officially and/or statistically identified as being homeless (Kauppi et al., 2017). Invisible or hidden homelessness includes individuals and families who are couch surfing (staying with friends or family temporarily), overcrowding or sharing accommodations, and residing in institutional or impermanent housing such as prisons, hospitals, tents or motels (Kauppi et al., 2017).

## Palliative Care:

According to Hospice Palliative Care Ontario (HPCO), palliative care is defined as a holistic form of health care that includes improving quality of life and treating pain and suffering involving physical, psychological, emotional, spiritual, and social aspects of those living with a life-limiting illness as well as their family and those of whom they identify as family (2016).

## Service User:

Includes those who seek and utilize health or social programs, resources, and services in a client capacity.

## Service Provider:

Includes those who provide health care (e.g. Doctor, Registered Nurse Practitioner, etc.) or social services (e.g. Social Workers, Counselors, etc.) to service users or clients.

## Vulnerable Population:

In relation to healthcare and social privilege, a vulnerable population can be defined as being disadvantaged due to discriminatory beliefs or stereotypes that effectively diminishes their capabilities for effectively making their own decisions, accessing resources, and being treated with equality (Waisel, 2013). Common characteristics among people within a vulnerable population include "racial or ethnic minorities, children, elderly, socioeconomically disadvantaged, underinsured or those with certain medical conditions...[who] often have health conditions that are exacerbated by unnecessarily inadequate healthcare" (Waisel, 2013, p. 2).

## Vulnerably Housed:

Was initially perceived as individuals or families having their own residence but had experienced bouts of homelessness or moved at least two times within the last year, but the results of a study conducted by The Research Alliance for Canadian Homelessness, Housing, and Health (REACH 3) in 2010 determined that those who were homeless and vulnerably housed experienced similar transitions between the two housing states, thus they presently define them into one group or population (2010).



# Introduction

The government is seeking better care for Ontarians at end-of-life while managing health care resources over time. In 2011, a multi-stakeholder report titled “A Declaration of Partnership and Commitment to Action” was developed to outline a vision for palliative care in Ontario (Declaration of Partnership and Commitment to Action, 2011). The stated vision is that “adults and children with progressive life-limiting illness, their families and their caregivers will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to help them live as they choose, and optimize their quality of life, comfort, dignity and security.” (Declaration of Partnership and Commitment to Action, 2011, p.7). In 2014 the North West Local Health Integration Network (LHIN) developed a Regional Palliative Care Program (RPCP) with the goal “to develop a comprehensive plan to mobilize, strengthen, and reorient the health care system to improve access to safe, comprehensive, and high quality palliative care for all residents of Northwestern Ontario”. In 2016, the Palliative and End-of-Life Care Provincial Report was tabled by Parliamentary Assistant, John Fraser to respond to the 2011 Declaration of Partnership. The report captured roundtable discussions from invested stakeholders in Ontario around palliative care and provided observations and key elements for successful palliative care models. As a result of this work, in 2016, the Minister announced the launch of a new Ontario Palliative Care Network (OPCN), a partnership of community stakeholders and health system planners who are developing a coordinated standardize approach for delivering palliative care services in the province. OPCN will act as the Ministry’s principal advisor to palliative care, drive quality improvements, and monitor system-level performance.

Following the work completed to date the Ministry invited Local Health Integration Networks in partnership with health and social service providers and community members to submit proposals for projects that improve hospice and palliative care for people who live homeless and/or vulnerably housed in Ontario.

This project aligns with Canada’s Truth and Reconciliation Commission (TRC) Call to Action regarding the charter of rights for the homeless and vulnerable populations concerning equitable access to palliative care (Truth and Reconciliation Commission of Canada [TRCC], 2015). The project also coincides to the following calls to action of which were presented at this year’s

(2018) Hospice Palliative Care Ontario Conference in Toronto by Joanna Vautour and Usman Aslam (Cancer Care Ontario).

Vautour and Usman cited 7 Calls to Action related to health outcomes, which relate to the work carried out in this palliative care needs assessment;

1. Implementation of Jordan’s Principle
2. Establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities
3. Recognize, respect and address the distinct health needs of the First Nations, Inuit and Métis people
4. Provide sustainable funding for existing and new Aboriginal healing centres
5. Recognize the value of Aboriginal healing practices
6. Increase the number of Aboriginal people working in healthcare and provide cultural competency training for all healthcare professionals
7. Include Aboriginal health issues in medical schools. (J. Vautour, personal communication, May 3, 2018)

Ontario is divided into 14 Local Health Integration Networks (LHINs) that are responsible for funding, planning, and integration of local health care and services that include the delivery and coordination of community and home care (Local Health Integration Networks [LHIN], n.d.b). With the lowest population as well as population density in the province (231,000 people and 0.5 people per square kilometer), the North West LHIN has a large geography (47% of the province) and a relatively small, dispersed population that results in challenges to health service delivery, including access to care, health human resources, the need for extensive travel, and higher costs of care per capita (LHIN, 2015a; LHIN, 2014; LHIN, n.d.c). The communities within the North West LHIN are spread across 458,010 kilometres from Hudson Bay in the North to the United States border, and from the Manitoba border to just west of White River. The North West LHIN is sectioned into 5 regions that are

identified as LHIN sub-regions which include: the District of Kenora, the District of Rainy River, the District of Thunder Bay, the City of Thunder Bay, and the Northern District (LHIN, n.d.b; LHIN, n.d.c). With 67 First Nation communities, the North West LHIN has the highest proportion of Indigenous people (20.5%) within an Ontario LHIN region, while representing only 2.0% of Ontario's total population and 9.9% of the Indigenous population within the city of Thunder Bay (LHIN, 2015a). More than two-thirds of communities do not have year-round road access, with some accessible only by air. The health status of Indigenous people in Canada is poorer than non-Indigenous people on most measurable health indicators, and the Northwest region is no exception.

Data shows that the Indigenous population is under-employed with a much lower median household income, a much higher rate of unemployment and higher rate of chronic conditions (Kauppi, O'Grady, Schiff, Martin, & Ontario Municipal Social Services Association, 2017). As a population, they are over-represented in the number of people who are homeless and requiring help to manage addictions and other health issues (Ontario Aboriginal Housing Services, 2016). Various local reports suggest Indigenous people are significant users of shelter homes. A recent point in time report (2016) showed that of all the homeless people

interviewed in Thunder Bay, 74% were of Indigenous identity (City of Thunder Bay, 2016). At the time of writing this report a 2018 Point in Time survey was conducted but official results had not yet been released.

Poverty and homelessness are growing socio-economic issues locally and nationally. Homeless and vulnerable populations living with life limiting/ threatening and terminal illnesses often are identified late and die early without access to high quality palliative care (Cipkar & Dosani, 2016). There is stigma, discrimination, racialization, and trauma known to be associated with the provision of care from social institutions (Cipkar & Dosani, 2016). These practices create significant barriers to palliative care identification, and access to quality end-of-life care.

As a preliminary question to begin the dialogue as a group we sought to understand what is happening with people facing life-limiting illness who live homeless or are vulnerably housed? What is occurring in the urban, rural and remote regions of Northwestern Ontario? What strengths and challenges exist in the current system? How as a region do we or can we respond with execution of recommendations to address these challenges?

## Purpose of the Survey

The purpose of the survey was to form the basis of a needs assessment informed by service users with lived experience and service providers to determine what is occurring in our LHIN and provide meaningful input in bridging recognized gaps. The purpose of the needs assessment was to identify the needs of the vulnerable, underserved population and those who are homeless in our region. The needs assessment provided evidence-based information on current gaps and causes of those gaps, and identified priorities, opportunities, and possible solutions to address system gaps in accessing palliative care services for the target population.

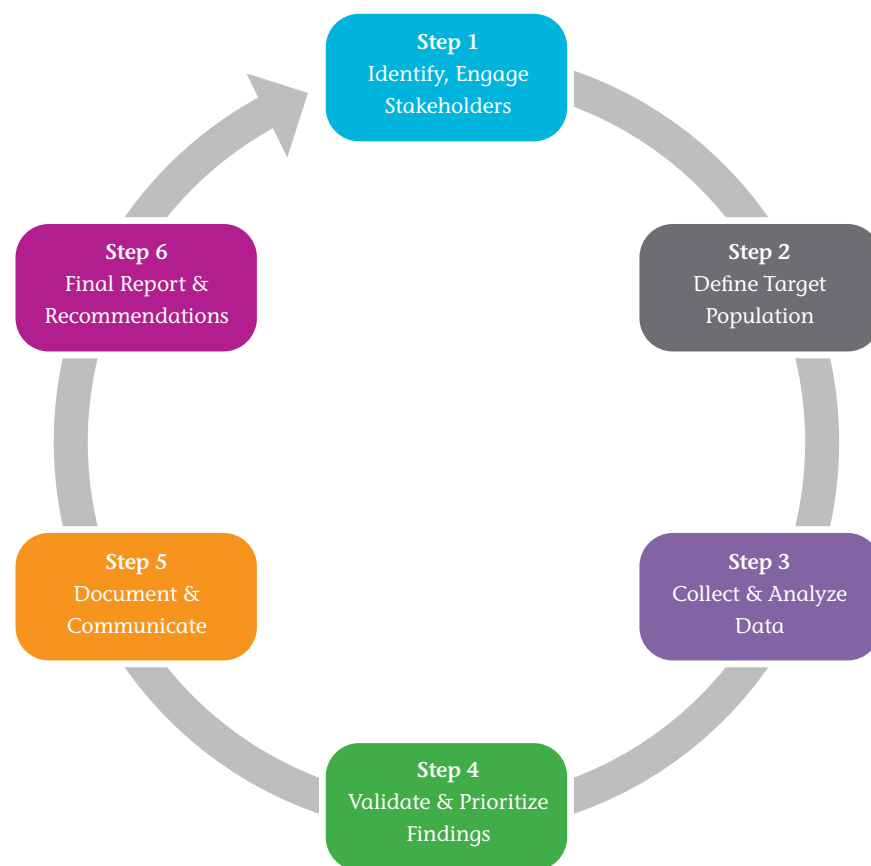
# The Approach

Dilico Anishinabek Family Care was pleased to submit a proposal to the Ministry of Health & Long Term Care for the North West LHIN to explore current practices and best approaches for delivering palliative and end-of-life care services to people who are vulnerable and live homeless in Northwestern Ontario.

Dilico Anishinabek Family Care met with the North West LHIN, Regional Palliative Care Program, and community stakeholders in February 2017 to discuss a coordinated approach to conducting a needs assessment for the vulnerable homeless population. At the meeting it was determined that Dilico Anishinabek Family Care would conduct a needs assessment with the support of these initial partners while seeking to engage other subject matter experts and service providers as the project evolved. The Agency identified a project lead to coordinate and direct the palliative care initiative. A Partnership Advisory Team (PAT) was established to provide advice on the project scope and approach. Regular consultation with the Partnership Advisory Team supported the process, enabling the team to identify pertinent questions about delivery of services to rural and remote areas (See appendix A for the PAT Terms of Reference).

With the support of the North West LHIN and several health and social service agencies, Dilico Anishinabek Family Care sought to build meaningful partnerships with local health and social service stakeholders to carry out a community minded needs assessment and evaluation of what is currently occurring in our region to determine the best approaches for delivering palliative care services. The project attempted to survey people who live homeless and or are living vulnerably housed across the region, recognizing a majority of the population would be Indigenous. In keeping with Indigenous worldview Dilico Anishinabek Family Care adheres to the principles of Indigenous research methodologies. These principles include: everything is relationship based, all things are connected, and working collectively. Context is important and stories tell us how to move forward together. We further adopt the work of Kirkness & Barnhardt's 4 R's – all work is to be respectful of one another, relevant, reciprocal, and we all have responsibility in the work we complete together (2016).

The following steps were identified to lead and guide the process (see diagram below):



For further detail regarding how each step was addressed, see Appendix B.

The following section outlining the region's current state will provide a more defined picture by identifying existing statistics and characteristics relating to the vulnerable/marginalized population; palliative care providers, promising practices, current programs, and regional resources.



# Environmental Scan

## Target Population Characteristics

The target population for this report pertains to those who are included as members of the vulnerable/marginalized population, in particular those who have experienced homelessness and/or being vulnerably housed. There remains a scarcity of statistical and descriptive information concerning the vulnerable and underserved population including data regarding the homeless and invisible homeless populations, as well as Indigenous homelessness. There are no current sources of information that can truly provide a completely accurate picture of the vulnerable population, but it is now possible to utilize pertinent data from Point in Time Counts along with shelter occupancy numbers, subsidized housing wait lists, core housing need, and academic articles to develop a clearer depiction of this population and their associated characteristics.

The Canadian Observatory on Homelessness published a report, *The State of Homelessness in Canada 2016*, which states that in Canada, on any given night 35,000 people are homeless, and homelessness is experienced by approximately 235,000 or more Canadians per year. Women comprise 27.3% of these numbers and 18.7% are youth, and homelessness among older adults and seniors is on the rise (Canadian Observatory on Homelessness, 2016). The Indigenous population makes up approximately 28-34% of shelter occupants, and the average duration of shelter occupancy is twice as long for families as individuals (Canadian Observatory on Homelessness, 2016). Another source reports that “[sic] Native Canadians are 10 times more likely than non-indigenous to end up in an emergency shelter...[and] [n]early 1 in 5 native people who live off reserve are homeless” (Homelessness - The Facts, 2017, pg. 19).

Difficulties associated with obtaining statistics and data surrounding this population have not only been noted in urban areas, but are more challenging within rural and remote areas of Northern Ontario due to the levels of hidden homelessness resulting from stigma avoidance, the geographical component involving a lack of shelters and services, as well as the disparity of experiences and barriers (social, racial, gender, sexual orientation, and other barriers) that this population faces (Expert Advisory Panel on Homelessness, 2016; Kauppi et al., 2017; Ontario Aboriginal Housing Services, 2016). The statistics that are available paint a picture of the homeless population as having an overrepresentation of First Nation, Métis, and Inuit People in Ontario (Ontario Aboriginal Housing Services, 2016). For instance, the Homeless Hub website community profile of

Thunder Bay, ON, reported 289 individuals interviewed in the homeless count with 74% identifying as Indigenous (Homeless Hub, 2017; City of Thunder Bay, 2016). Overall, 47.8% of those interviewed reported to be couch surfing while 32.2% were staying at an emergency/domestic violence shelter (City of Thunder Bay, 2016).

Despite the limited data and characteristics that have been obtained thus far, we are able to get a glimpse of the diversity within the target population. Statistics Canada published a study surrounding hidden homelessness and reported the age groups experiencing hidden homelessness from highest to lowest was 35 to 44 (10.8%), 25 to 34 (10.5%), 45 to 54 (9.6%), 55 to 64 (8.2%), 65 to 74 (5.0%), 15 to 24 (4.8%), and the lowest being 75 and over (2.4%) (2016). The Hidden Homelessness in Canada study also noted that 29.9% of those experiencing hidden homelessness identified along the LGBTQ continuum and a marginal percentage reported being an immigrant (5.5%) or belonging to a visible minority group (4.3%) (Statistics Canada, 2016b).

Although this population can be described as heterogeneous and diverse, there are some common characteristics among this group. One of the commonalities that are found within the target population is the adversity to seeking medical treatment at regulated medical facilities due to fear of experiencing discrimination, and mistrust of authority figures such as health care providers and social workers, which presents a barrier to accessing palliative care (Collier, 2011; McNeil, Guirguis-Younger, & Dilley, 2012). Another shared characteristic among the vulnerable and underserved population pertains to their health trajectory, life expectancy, and comorbidities (Mikkonen & Raphael, 2010; Collier, 2011). The available research and statistics show this population to have a significantly reduced life expectancy (37 to 47 years) and a mortality rate up to 10 times higher than the national average, (Leung, Nayyar, Sachdeva, Hwang, & Song, 2015; Cipkar, & Dosani, 2016; Sumalinog, Hwang, Harrington, & Dosani, 2017).

According to Mikkonen and Raphael’s report outlining the Social Determinants of Health, predictors of poor health outcomes can be attributed to 14 indicators, some of which are income disparity, lack of stable housing, food insecurity, limited access to health services, gender, and Indigenous identity (2010). Many of these health disparity indicators are experienced among the target population in one form or another which contributes to negative health outcomes, as well as the comorbidity of chronic health conditions such as diabetes, chronic lung diseases, and cardiovascular diseases (McNeil, Guirguis-Younger, & Dilley, 2012; Jaworsky et al., 2016). Some other conditions and illnesses that are common among this population also include “higher incidences of substance use, severe mental illness, and infectious diseases such as HIV/AIDS and Hepatitis C” (McNeil, Guirguis-Younger, & Dilley, 2012, p. 1).

# Palliative Care Providers and Regional Resources

The following information concerns the existing local and regional resources pertaining to palliative care providers and programs within the North West LHIN region. Although there appears to be a lack of equitable resources for the vulnerable/marginalized population, this provides a unique opportunity to assess and evaluate current and promising programs and practices in order to develop appropriate and much needed services for all populations.

According to the North West LHIN Regional Palliative Care Program (St. Joseph's Care Group, 2018), the only formal palliative care medical services available within the region include:

- 5 Palliative Care Physicians for the entire North West LHIN region (all based in the City of Thunder Bay)
- 6 North West communities have received funding for hospice beds co-located in their community hospitals
- North West LHIN Home & Community Care End-of-life Program
  - 1.0 Full Time Equivalent (FTE) End-of-life (EOL) Care Coordinator
  - 5.0 FTE Hospice Palliative Care Nurse Practitioners (1 for each sub-LHIN region)
  - 2.0 FTE Complex Chronic Disease Nurse Practitioners (City of Thunder Bay)
- Palliative Pain & Symptom Management Program (LHIN Home & Community Care)
  - 1.0 FTE Registered Nurse or Nurse Practitioner (position vacant)
- St. Joseph's Hospital (Interdisciplinary Palliative Care Team)
  - 11 Bed Hospice Palliative Care Unit
  - 10 Palliative Care beds (Longer Term)
  - Pilot Non-Oncology Out-Patient Palliative Care Clinic (2 half days/month)
  - 24-7 Palliative Care Consultation Line for providers only (not clients/families)
  - 1.0 FTE Palliative Care Telemedicine Consultant, RN

- Thunder Bay Regional Health Sciences Centre
  - 0.8 FTE Palliative Care Clinician (RN)
  - 1.0 FTE RN for Pain and Symptom Management Clinic
  - Oncology Out-Patient Palliative Care Clinic

Formal Palliative Care Education, Respite & Volunteer Services:

- Centre for Education and Research on Aging & Health (CERAH) at Lakehead University
  - 1.5 FTE Palliative Care Education Planner
- Hospice Northwest
  - 120 Hospice Volunteers in the City of Thunder Bay & District of Thunder Bay
- Kenora-Rainy River District Palliative Care Volunteer Program
  - Approximately 100 trained volunteers
- Wesway Respite Service
  - Provides crisis respite, access to a respite support home, and in-home services to relieve caregivers

## Current Programs, Resources, and Research

Current programs and resources vary across the North West Region. For example, North of Red Lake, which is located slightly above the 51st parallel in Ontario, there is a complete absence of funded Indigenous Friendship Centers, Indigenous health teams, Indigenous Community Health Centers, or Indigenous Health Access Centers (LHIN, n.d.a). North West Local Health Integration Network reports indicate there are only 8 Indigenous Friendship Centers, 3 Indigenous Health Access Centers, one Indigenous Family Health Team, and no Indigenous Community Health Centers within the North West LHIN region (n.d.a). However, the First Nations and Inuit Health Branch (FNIHB) that operates within the Department of Indigenous Services Canada provides some First Nations and Inuit Programs and Services within various communities surrounding public health, primary care, non-insured health benefits, and community programs (Health Canada, 2008; Department of Indigenous Services Canada [DISC], 2018). The FNIHB currently lacks sufficient funding and resources to effectively run existing programs or to even consider implementing new services such as palliative care.

The North West LHIN has established 14 Local Health Hubs (LHHs) that are working to provide communities with integrated health services (North West LHIN, n.d.). Ten of these LHHs have a North West LHIN Home and Community Care (HCC) office (formerly Community Care Access Centre) that facilitates access to various health care programs and resources (e.g. End-of-life and Palliative Pain and Symptom Management programs), for community members through a formal (e.g. health care provider) or informal (e.g. self or family member) referral and registration process (Ontario Hospital Association, 2015; Northwesthealthline, n.d.; Home and Community Care NWLHIN, 2017).

In 2014, all 14 LHINs in Ontario committed to recognizing palliative care as a priority for system transformation, and to developing a regional implementation plan (North West LHIN, 2014). The North West LHIN's Regional Palliative Care Program with St. Joseph's Care Group. As part of the Regional Palliative Care Program's current work plan, equitable access to palliative services for vulnerable populations has been identified as a priority (Ontario Palliative Care Network, n.d.). While the North West LHIN Regional Palliative Care Program plans to prioritize access for vulnerable populations, there are no formal programs or services within the region to address the target population's palliative care needs. Some of the reasons for the gaps in palliative care services provided to the target population could be due to the lack of research surrounding the homeless and vulnerably housed population, the perceived/experienced barriers of this population (fear of discrimination/distrust), and the differing values, needs and priorities surrounding palliative and health care needs (Sumalinog, Hwang, Harrington, & Dosani, 2017; Collier, 2011; Hudson, Flemming, Shulman, & Candy, 2016). The limited number of dedicated palliative care services in the North West LHIN region is also a factor in being able to deliver care to the target population.

## Promising Programs & Possible Opportunities

There are some promising recommendations and pilot programs within the literature to address the gaps in service experienced by the target population, such as: bringing the palliative care program and resources to them through street outreach programs, increasing education to those delivering palliative care to the homeless; and partnering with local shelters (Collier, 2011; Hudson, Flemming, Shulman, & Candy, 2016; Sumalinog, Hwang, Harrington, & Dosani, 2017). The following discussion of current programs and practices of palliative care service

delivery to the target population may be assistive in developing palliative care services for the diverse target population within the North West LHIN region.

During Dr. Naheed Dosani's TED Talk, "What's a life worth?", he contemplates if homelessness is a form of terminal illness due to its high mortality rate and states that for every one person you see in a shelter there are 23 others who are on the verge of homelessness, and each year housing vulnerability is experienced by one in five Canadian households (Dosani, 2016). This report identified two promising programs involving the delivery of Palliative Care services to the target population, one operates within Toronto, and the other is located within Calgary. Dr. Dosani is a palliative care doctor and lead of the Palliative Education and Care for the Homeless (PEACH) program through Inner City Health Associates (ICHA) in Toronto, Ontario that delivers mobile palliative care services to the homeless (ICHA, n.d.). The Calgary Allied Mobile Palliative Program (CAMPP) is similar to the PEACH program in that they bring a mobile component to the delivery of palliative care services as well as the dignity for their clients to die where they want and in comfort (Lee, 2017). Although the PEACH program and the CAMPP team may be useful within large urban centres like Toronto and Calgary, and the concept of bringing the service to the target population may assist in decreasing the barriers of accessing palliative care, geographical barriers and cultural differences within the North West LHIN will have to be taken into consideration.

The following programs offer possible opportunities to form linkages or collaborative partnerships to disseminate palliative care information to the target population. Similar to the PEACH and CAMPP programs, but without the palliative care component, the Street Outreach Nurse program through Thunder Bay District Health Unit offers "free, confidential, non-emergency support to the street-involved population including: Counselling and referral to services, Harm reduction services, Infectious disease follow up [and] Sexually Transmitted Infection (STI) testing and treatment" (NorthWesthealthline, 2018). Thunder Bay's NorWest Community Health Centres have created partnerships within the city to increase health promotion and medical access to vulnerable members of the community through establishing outreach locations for walk-in clinics (NorWest Community Health Centres, n.d.). As an example, two programs that provide health and social services to underserved and vulnerable populations are the Drop-in Clinic and, Kwae Kii Wiin Managed Alcohol Centre that are located within Shelter House Thunder Bay (Shelter House Thunder Bay, 2018a; Shelter House Thunder Bay, 2018b). The city of Thunder Bay, through the partnership between Elevate Northwestern Ontario (NWO) and Joseph Esquega Health Centre, now have a remodeled ambulance that transports health care workers and resources to deliver street-based health care services to the homeless and marginalized populations (CBC News, 2018a). The North West LHIN has also just earmarked funds to support a new Joint Crisis Response Program that involves



the collaborative efforts between the Thunder Bay Police and local Canadian Mental Health Association to deliver mental health crisis interventions to the local population (CBC News, 2018b).

Another innovative collaboration and possible linkage opportunity involves the student-led interprofessional Compass North Clinic and the Shelter House Thunder Bay who are working together to complement existing services to effectively improve health outcomes for the target population (Strong, 2015). The Getting Appropriate Personal & Professional Supports (GAPPS) program is a LHIN funded collaborative outreach program within the city of Thunder Bay that seeks out and provides social, mental health and addictions services to the vulnerable/marginalized population who might not otherwise be able to navigate, engage or seek out these services on their own (St. Joseph's Care Group, n.d.; Canadian Mental Health Association [CMHA], 2012). The Sioux Lookout - Front St - Wellness and Recovery Centre program through the Sioux Lookout Meno Ya Win Health Centre also holds some similarities to the Street Outreach Nurse program where they partner with the Out of the Cold Sioux Lookout Shelter. The program offers assessments, assistance with locating housing, case management services, hospital social worker services, mental health and addiction counselling, networking and daily rounds at the Out of the Cold Shelter, problem gambling counselling, treatment referral and follow up, community outreach and education, and a lunch program for individuals in emergency situations (NorthWesthealthline, 2017). These programs may offer some constructive information surrounding potential models and possible opportunities to assist in formulating an appropriate program for the target population.

Partnering palliative care services/resources with homeless and other emergency shelter organizations may provide opportunities to break down barriers and provide equitable access to palliative care for the target population (Collier, 2011; Hudson, Flemming, Shulman, & Candy, 2016; Sumalinog, Hwang, Harrington, & Dosani, 2017). The FNIHB, with additional funding, could incorporate palliative care services within existing programs, or work collaboratively with other programs or agencies to increase delivery of palliative care to the target population.

Another consideration that could be incorporated within the North West LHIN region would include the development of community-based palliative care initiatives/programs that align with the culture and traditions of the potential service users. For example, the formation of a Palliative Shared Care Outreach Team was successfully created in Six Nations of the Grand River Territory as part of the participatory action research project "Improving End-of-Life Care in First Nations Communities (EOLFN)" based out of Lakehead University (Fruch, Monture, Prince, & Kelley, 2016). The project, based on a community capacity development approach, recognized that First Nations have a vast amount of traditional and

community-based knowledge in the complexities around end-of-life experiences; however, western health systems do not typically support less mainstream approaches to care (Prince, Mushquash, Kelley, 2016).

Additional consideration may also be given towards implementing something similar to a housing first strategy, such as what was put forth by former minister Sir Ed Davey in the United Kingdom, where he has petitioned to change the law in order for terminally ill homeless individuals to be immediately eligible and offered housing so they can die with dignity and not on the street (Buchan, 2018). The Homeless Initiative Program (HIP II) involves a homeless reduction strategy and links to other services through providing subsidized housing units throughout the city of Thunder Bay to those who are presently struggling with serious mental illness and are homeless or at risk of being homeless (Alpha Court, n.d.; CMHA, 2013). An examination of the HIP II model could be assistive in developing a similar program or linkages to palliative care resources for the target population. However, implementing such a strategy within the North West LHIN area could prove to be challenging due to the geographical makeup of the region and the inadequacy of housing resources in the northern communities (Statistics Canada, 2017). Dilico Anishinabek Family Care currently runs three youth targeted housing programs/initiatives (Homes for Good initiative, Housing Outreach Program Collaborative (HOP-C), and Transitional Housing for Youth Leaving Care) to prevent homelessness by offering various supports in transitioning from care to the community (Y. Wanakamik, personal communication, May 3, 2018). These programs could also offer examples of appropriate intervention and possible model development with the target population regarding palliative admissions to the hospital and implementing a housing first strategy.

There are currently no services/agencies that are specifically mandated to provide formalized palliative care services for the target population. Although the target population could access mainstream palliative care services, there remain multiple complexities and barriers that inhibit equitable access. The removal of barriers and the establishment of equitable access to palliative care for this diverse population remains a priority for dignity and comfort, as well as a challenge. Promising programs and practices developed and implemented elsewhere provide valuable information that may be adapted and utilized in constructing a palliative care program for vulnerable populations that could be modified to each community or Local Health Hub. The "Innovative Models of Community Palliative Care for Vulnerable and Underserved Populations" project and survey results allows the chance to investigate needs and opportunities, provide recommendations, and assist in developing appropriate palliative care services for the target population.

# Survey Results Summary

To best understand what is occurring in the area of people who live homeless and vulnerably housed and may have chronic diseases and/or require a palliative approach to care the Partnership Advisory Team agreed to conduct a community needs assessment. Two surveys were established, one for service users (see appendix C) and the other for service providers (see appendix D). Service user data were collected through paper and pencil survey format. This data was manually entered into an Excel spreadsheet. Service provider data collected via an online survey website (SurveyMonkey) were pulled into an Excel spreadsheet.) Descriptive statistics were calculated in Excel by quantifying responses. Graphical images were created to display the results.

The majority of service users identified as Indigenous, spoke English as a first language, and had a high school education. Many service users did not have stable housing options, with emergency shelters as the most commonly reported place of residence. If service users were sick they tended to utilize emergency room or walk-in clinic services, since many did not have a primary health care provider. Community was an important factor for many service users who often relied on family and friends for help with transportation to and from appointments and for social support when sick. Time with family or friends was noted as the most important factor if an individual were to be diagnosed with a life-threatening illness.

The majority of service providers were female, Caucasian, spoke English as a first language, and had completed post-secondary education. Service providers worked in many different sectors and although the majority of service provider workplaces did offer palliative care services, over half of the service provider group had not received any formal training related to palliative services. Service providers expressed belief that everyone has a right to receive and access care and clients deserve to be treated with understanding, trust, compassion, respect, an open-mind, with dignity, and without judgment. The service providers also noted the benefit of using a humanistic approach as well as the importance of humour, sensitivity, and taking the time to listen.

Both service user and service provider groups emphasized that palliative care services are important and needed. Currently, several barriers exist that interfere with the provision of services for vulnerable individuals who need them. One of the most commonly reported barriers by both service users and service providers was the need for additional educational resources. Both groups emphasized the need for clients to be fully informed of their diagnoses and treatment options, yet service providers noted that they often did not know what palliative services were available to those in vulnerable populations.

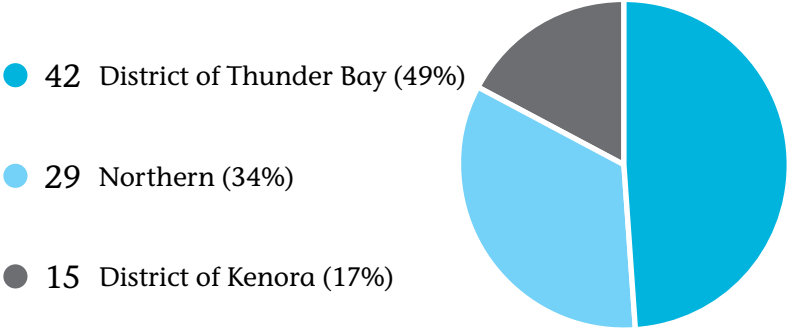
Service users and service providers reported a lack of help seeking by individuals experiencing severe illness and distress. Stigma, racism, and discrimination were mentioned as possible explanations for this disturbing trend. Service users called for increased sensitivity in palliative care situations to remedy this. Difficult and discriminatory admission criteria was an additional barrier to accessing care for many vulnerable service users, especially those who did not have a health card, identification, or fixed address.

Both service users and service providers noted the need for more care providers and more accessible services, especially within remote communities. Service providers understood that these problems were largely based in the need for additional funding. There were also logistical issues involved in providing care to a population that do not have stable housing, such as difficulty identifying those who are in this vulnerable population and difficulty maintaining contact with homeless or vulnerably housed clients.

# Service User Survey Results

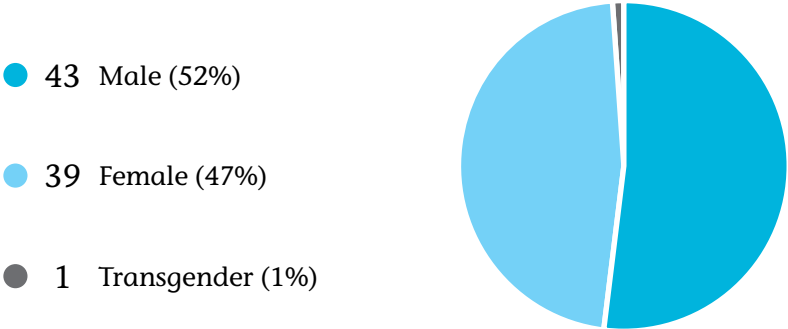
**86** Total Number of Service Users who took part in the study

## District of Location of Service Users

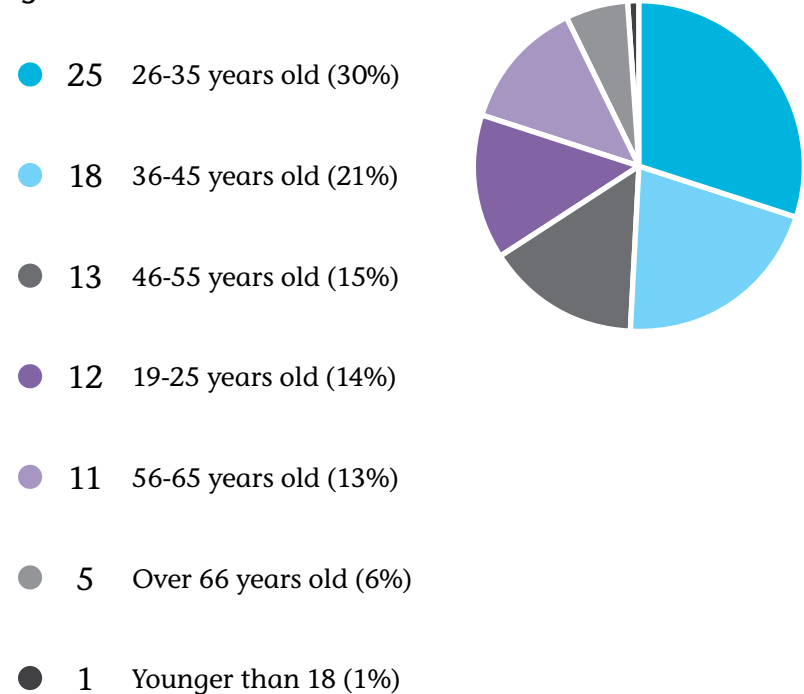


## Demographic Information

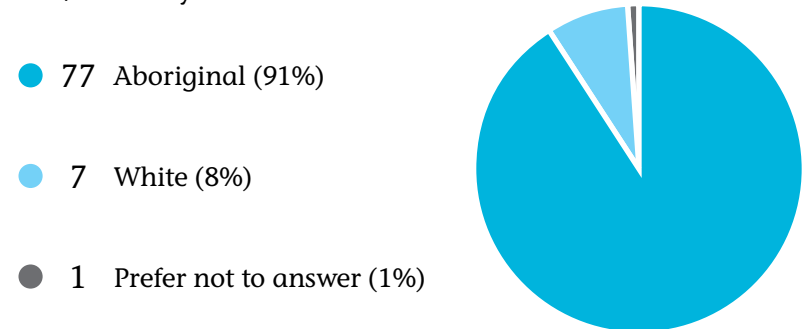
### Gender Identification of Service Users



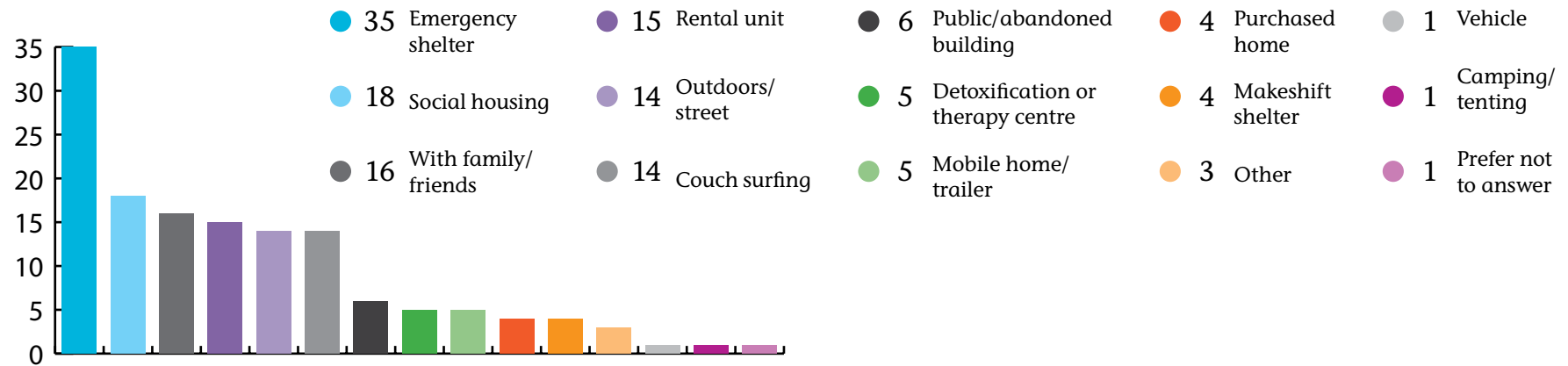
### Ages of Service Users



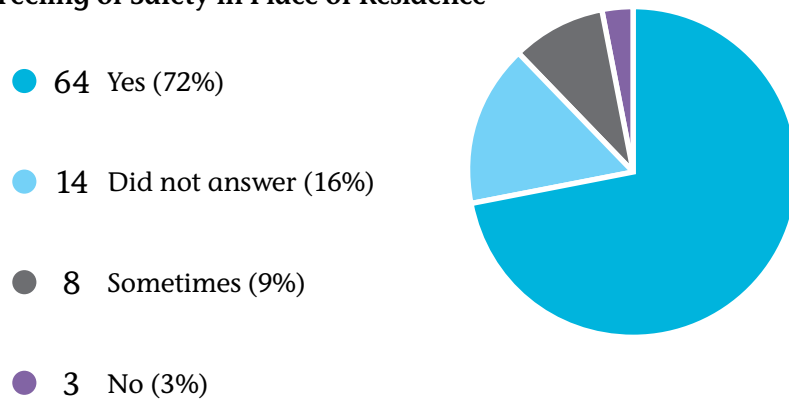
### Race/Ethnicity Identification of Service Users



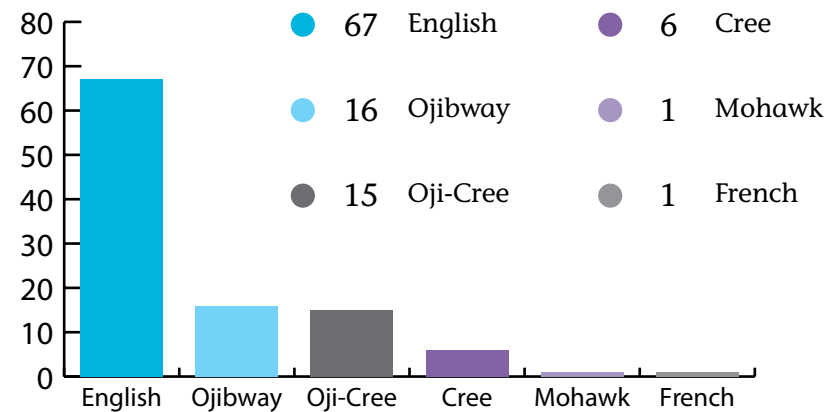
### Place of Residence



### Feeling of Safety in Place of Residence



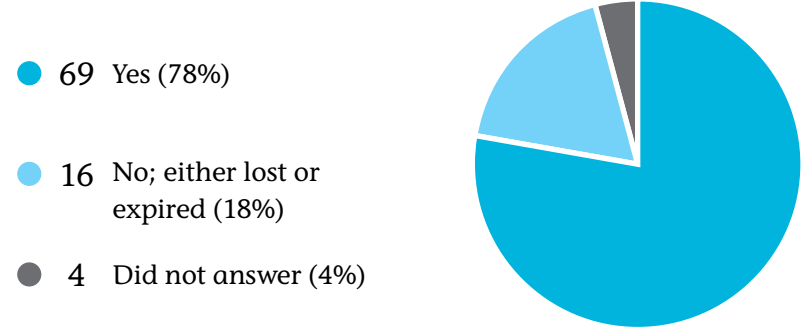
### Languages Spoken at Home by Service Users



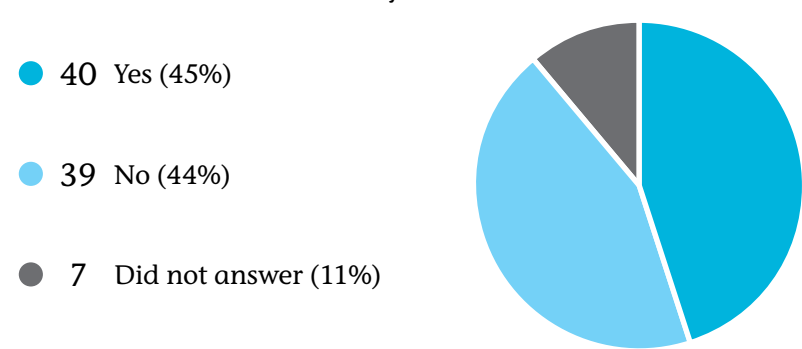


# Health Related Questions

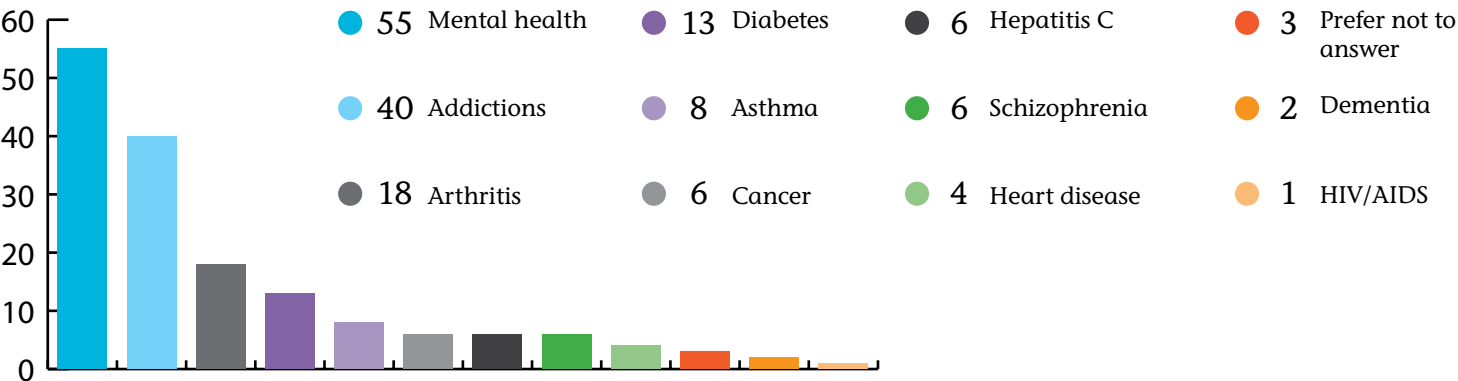
Do Service Users Have a Health Card?



Do Service Users Have Primary Health Care Providers?

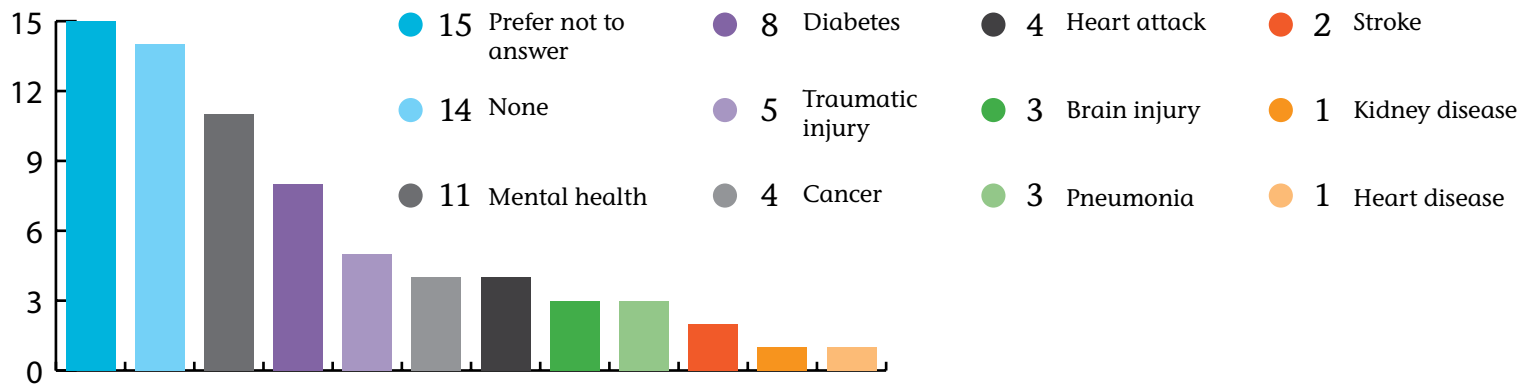


Diagnosed or Treated Health Conditions



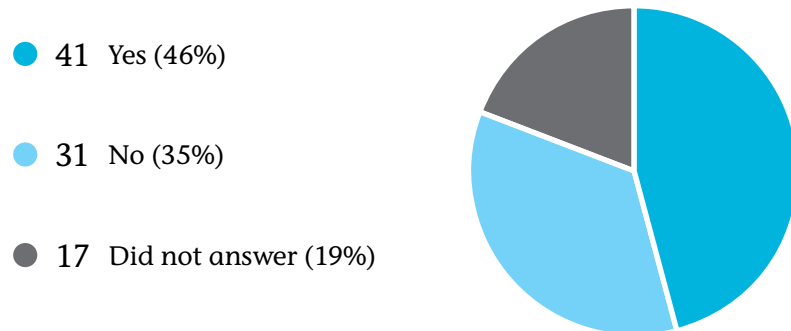
Service users were asked to report if they had been diagnosed with or treated for particular health conditions. Fifty-five individuals reported being diagnosed with or treated for mental health, 40 for addictions, 18 for arthritis, 13 for diabetes, and 8 for asthma. Of those diagnosed with or treated for mental health difficulties, 23 individuals reported depression, 9 reported post traumatic stress disorder, and 2 reported bipolar disorder.

## Health Challenges in the Past Year



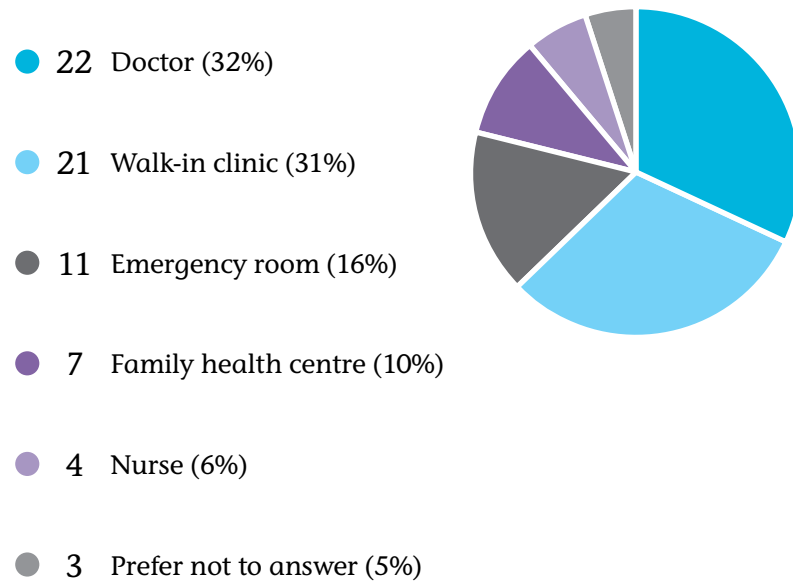
Service users were also asked if they had any health challenges in the past year. The majority of individuals preferred not to answer this question (15 individuals). Fourteen reported having no health challenges in the past year, 11 had mental health challenges, 8 had diabetes related challenges, and 5 had traumatic injuries. The types of cancer indicated include cervical, rectal, and prostate cancer. Some individuals noted additional health problems they had experienced that were not covered in this survey. These include liver problems, rape, infection, depression, anxiety, seizures, injuries, concussion, mobility issues, and amputation.

## Do Service Users Go for Regular Health Checkups?

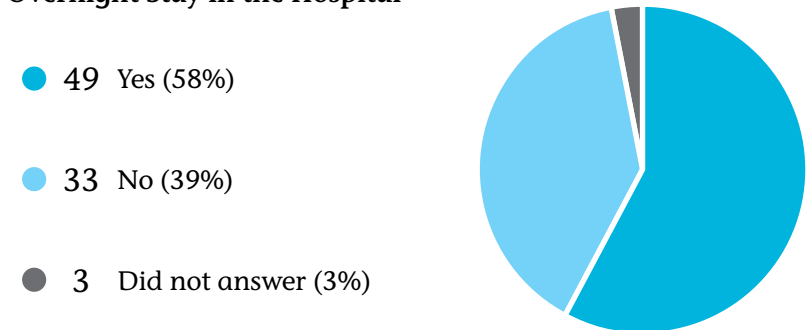


Service users were asked where they would go for help if they were sick. The vast majority of service users indicated that they would go to a hospital (45 individuals), emergency room (25 individuals) or walk-in clinic (22 individuals). Some users noted that they would go to their family doctor (6 individuals). A couple of service users mentioned turning to a shelter, nursing station or their mother when sick. Some individuals mentioned a reliance on family or neighbours to transport them to the nearest hospital and the need to travel long distances to seek services. One service user mentioned an inability to seek services anywhere due to an invalid health card.

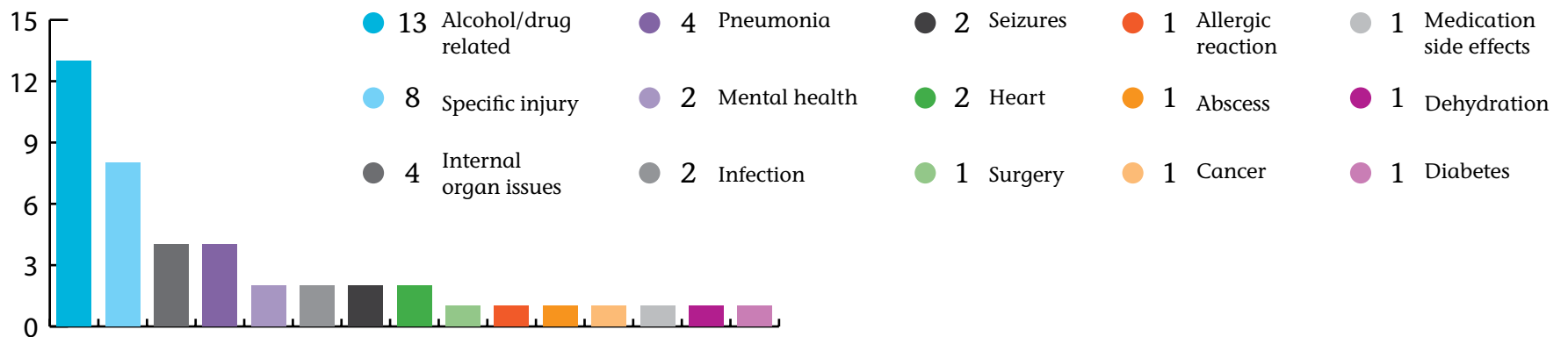
### Where Regular Health Checkups Are Received



### Overnight Stay in the Hospital

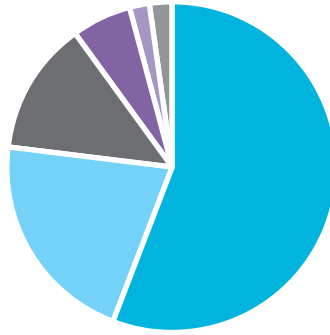


### Reason for Overnight Hospitalization



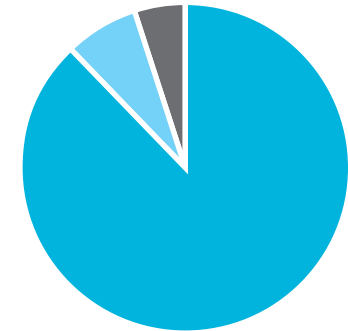
### Number of Visits to the Emergency Department in the Past Year

- 46 1-5 Times (56%)
- 17 6-10 Times (21%)
- 11 None (13%)
- 5 Did not answer (6%)
- 2 11-15 Times (2%)
- 2 16+ Times (2%)



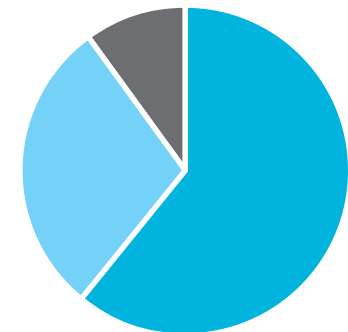
### Comfort Speaking About Health Conditions

- 72 Yes (88%)
- 6 Did not answer (7%)
- 5 No (5%)

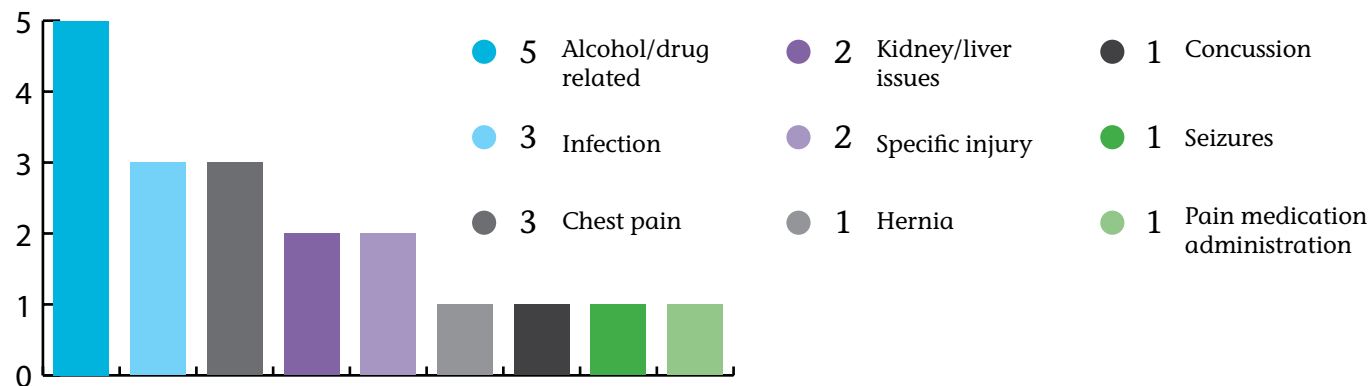


### Comfort Speaking About Death and Dying

- 52 Yes (61%)
- 25 No (29%)
- 8 Did not answer (10%)



### Reason for Emergency Department Visits

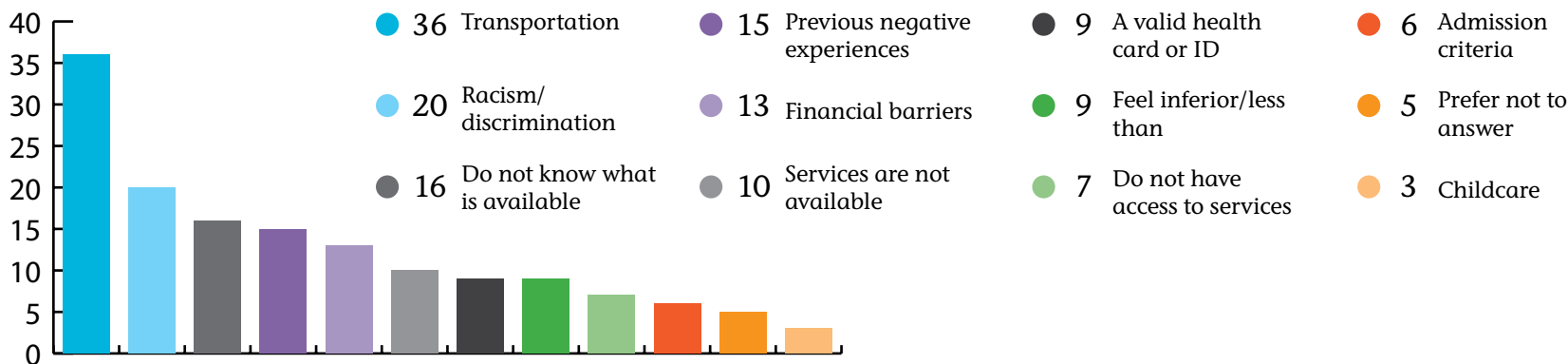




Service users were asked who they turn to when they are sick. The majority of service users noted that they would turn to their friends, family or partner if they were sick. Many specifically mentioned seeking support from family to talk about their illnesses. Support from specific medical professionals was also commonly sought from: walk-in clinics, hospitals or primary health care providers. A small amount of service users mentioned seeking support from shelter staff or religion.

A group of service users mentioned that they would not seek help from anyone when they are sick. Various reasons were mentioned to explain why this was the case. Some individuals mentioned that seeking services from medical professionals was a last resort only for emergency services, indicating that they would rather be alone when sick. Some service users also mentioned not seeking help because they were supporting their family and saw that they had to be strong to help others. Finally, one individual noted that they lived on the street and did not have anyone to seek help from.

Challenges Faced Accessing Health Services



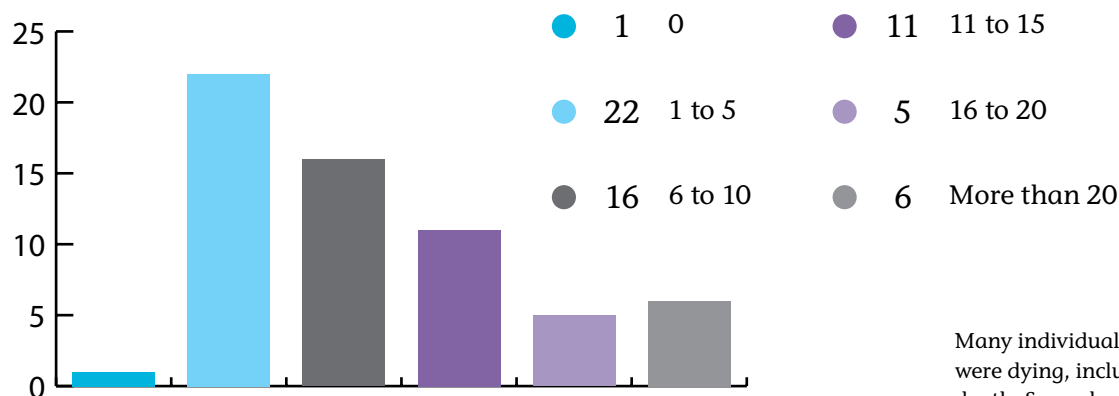
Service users were asked how health services could change to meet their needs. The most common suggestion was to have more accessible health care providers and walk-in clinic; specifically from non-emergency services. Service users suggested more community services and home visits should be available. Many service users also mentioned the need for physicians, nurses and social workers on-site at shelters and the availability of nursing services for those living on the street. A couple of service users also mentioned the need for more Indigenous nurses and doctors. Transportation to regular appointments and hospital visits was also often mentioned as a barrier in accessing health services. Many individuals mentioned the need to travel long distances to access services and not being able to take off time from work to do so. Several service users suggested the availability of free bus tickets would help to allow them to reach hospital services.

Service users noted the need for more respect from their health care providers. Specifically, less discrimination, aiming to gain a better understanding of client

experience, avoiding making assumptions and being more patient with service users. Service users also mentioned the need for services to be available faster. Some individuals also mentioned that they wanted more communication about available services from health care providers and increased awareness of available services. One individual noted that client treatment planning could be improved. Several individuals noted a need for safe injection sites and counselling services as well.

Service users were asked whether they preferred a specific ethnic or racial background, age, gender or membership in their community when choosing a health care provider. The vast majority of service providers indicated that none of these factors mattered to them, as long as they received competent care and equal treatment to others. Some individuals mentioned that they would prefer to see a health care provider of the same gender. One service user mentioned that past abuse made them reluctant to seek care from male health care providers. One individual preferred to be seen by an Indigenous health care provider.

## How Many People Service Users Knew That Passed Away in the Past 2 Years



Many service users were not aware of the care that was received by those who had died within the past two years. About fourteen respondents noted that proper services were provided, and about ten respondents noted that proper services were not provided. Of those who did not receive proper services, many explanations were given. One of the most common reasons for not receiving care were individuals not seeking care services that were available. Many service users noted that deaths were caused by individuals not seeking services until their health problems led to death. Service users noted a need for increased resources in First Nations communities, better transportation availability and closer emergency services.

A majority of the causes of death reported by service users involved addictions-related issues. Service users noted a need for rapidly available detoxification services and naloxone kits to avoid overdose. Individuals also noted the need for proper addictions care services to help prevent these deaths. Other service users noted deaths caused by murder, suicide, health problems (diabetes, stroke or heart attack), natural causes and medical error. A lack of stable housing and home care was attributed to be the cause of one death.

Service users were asked what would be most important to them if they were diagnosed with a life-threatening illness. The majority of service users indicated that time with family and friends would be most important to them. This included making arrangements for their own death, ensuring the wellbeing of their family, and saying goodbye to their loved ones. One service user mentioned the importance of fully understanding their diagnosis to allow them to communicate this with their family and friends. Some service users mentioned the importance of privacy during this process. Service users also noted the importance of accessing counselling, addiction services, cultural support and religious services while dying.

Many individuals indicated that they would want to be comfortable as they were dying, including the importance of pain management services and assisted death. Several respondents mentioned that they would like to die quickly rather than enduring a prolonged dying process. On the other hand, some service users indicated that they would want to enjoy the time before death with activities like travelling, sharing their story and other “bucket list” items.

Many individuals specified a specific location where they would like to die. Some individuals specified that it was important to them to die at home or in their home community. Other individuals mentioned the importance of dying in hospital. A few individuals noted that they would like to die alone or in a secluded area.

Service users were asked to provide suggestions for improvements to care for life-threatening illnesses. Service users stressed the importance of palliative care services that would allow individuals to be at home while they were dying, and the need for companionship and family involvement in end-of-life care. Supportive senior housing for those living outside the home was also suggested by a service user. One service user mentioned the importance of allowing visitors in to hospital rooms at any time to allow for family visits, and a need for private hospice rooms.

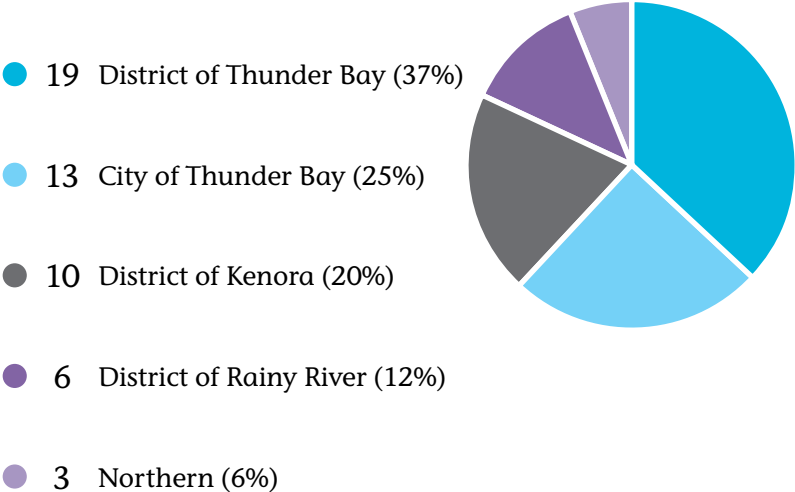
Several service users mentioned the need for service providers to be non-judgemental and have sensitivity for the situation that the client is in. They stressed the importance of telling the client the truth about the severity of their illness. The availability of counselling, traditional healing, addiction services and religious services were also important to service users.

Service users mentioned that police services, walk-in services, street nursing, transportation and Legal Will preparation were all important for palliative care situations. Respondents also suggested educational programs and help transitioning from work are needed. Several service users mentioned the need for social workers or other advocates to encourage help-seeking and ensure that individuals stayed in care as long as necessary to get better.

# Service Provider Survey Results

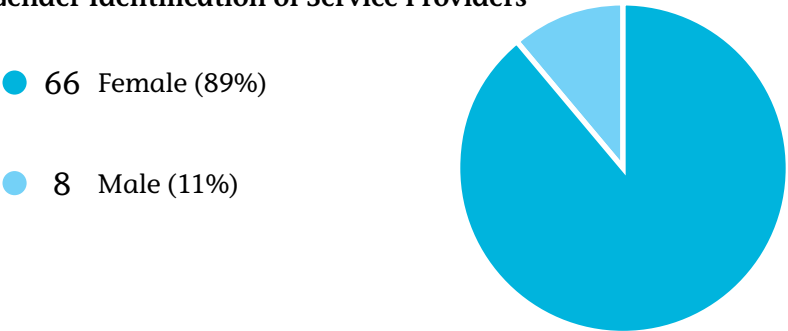
**74** Total Number of Service Users who took part in the study

## District of Location

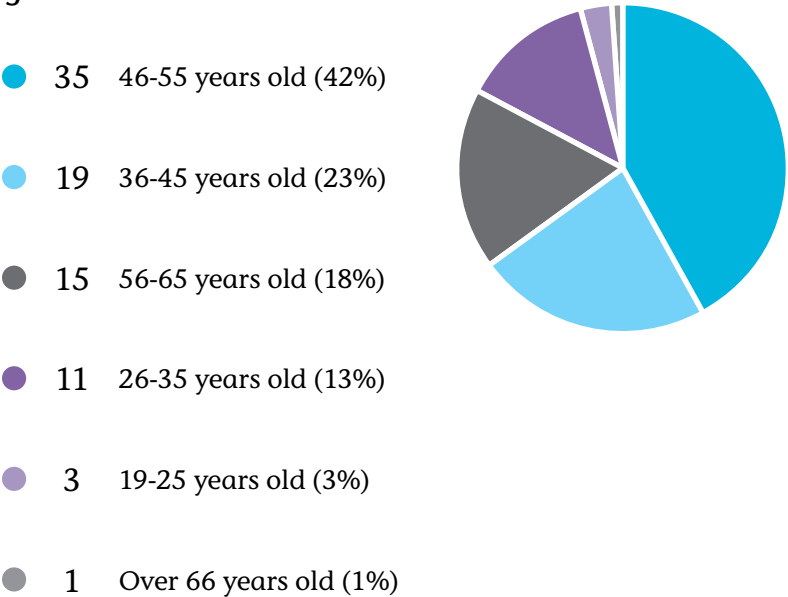


## Demographic Information

### Gender Identification of Service Providers

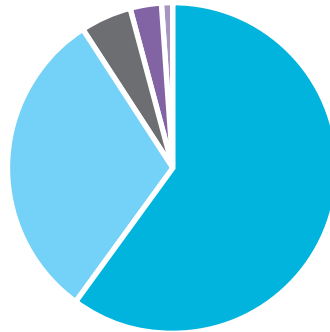


### Ages of Service Providers



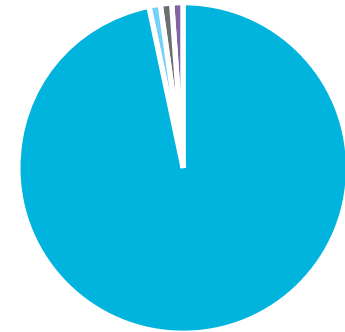
### Race/Ethnicity Identification of Service Providers

- 44 White (60%)
- 23 Aboriginal (31%)
- 4 Other (5%)
- 2 Prefer not to answer (3%)
- 1 Asian/pacific islander (1%)



### First Language of Service Providers

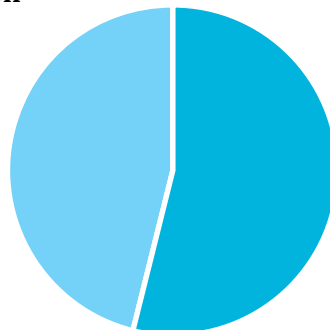
- 71 English (97%)
- 1 Ojibway (1%)
- 1 French (1%)
- 1 Prefer not to answer (1%)



## Palliative Care Information from Service Providers

### Received Training/Education Related to Palliative/End of Life Care as Part of Formal Education

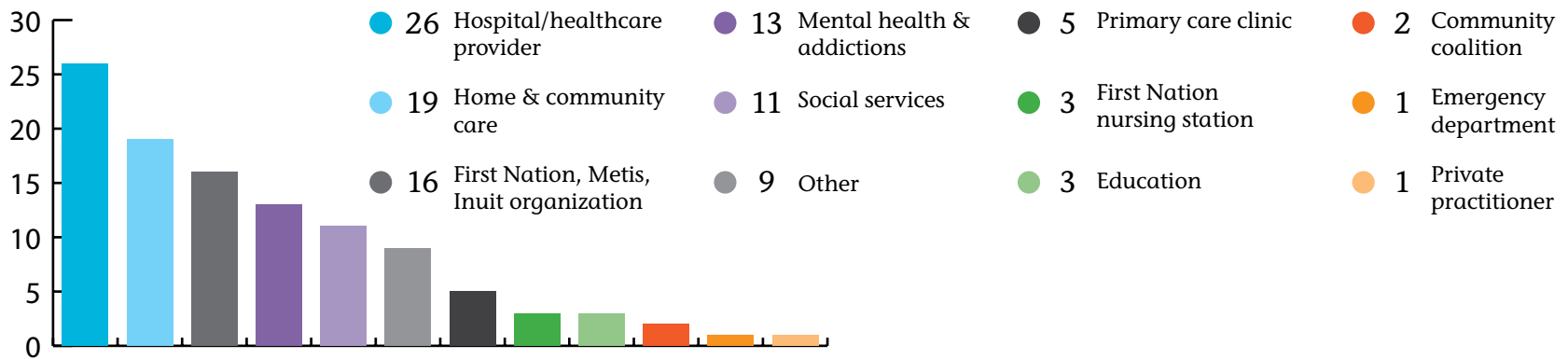
- 40 No (54%)
- 34 Yes (46%)



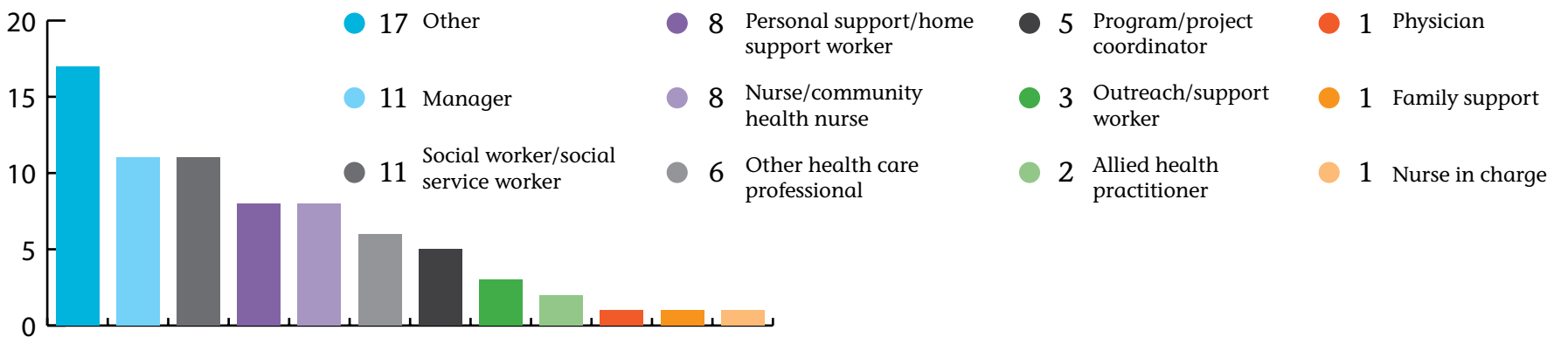
Of those who had received training or education related to palliative or end-of-life care as part of their formal education, this training was mostly received as part of a course during their educational training (e.g., PSW diploma, nursing degree); during a specific palliative care course, workshop, or seminar; or through clinical training at their place of employment. Additionally, many service providers reported that their training with palliative or end-of-life care came primarily from their years of experience in the healthcare field or through personal real-life experiences.



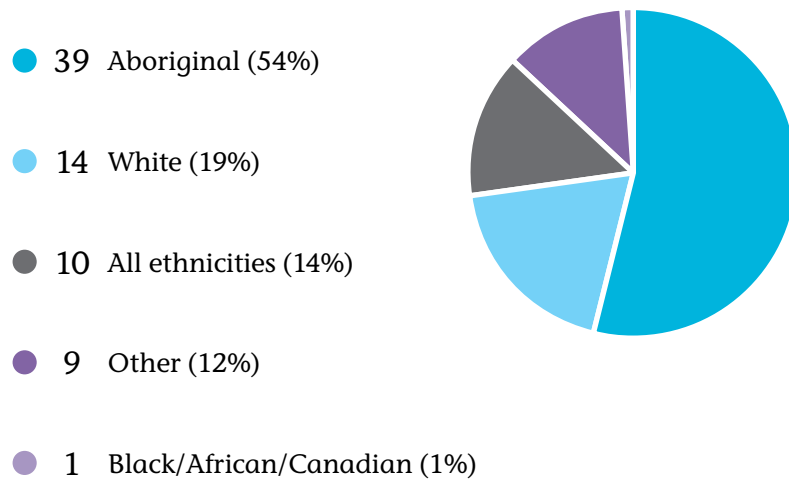
### Organizational Sector of Service Providers



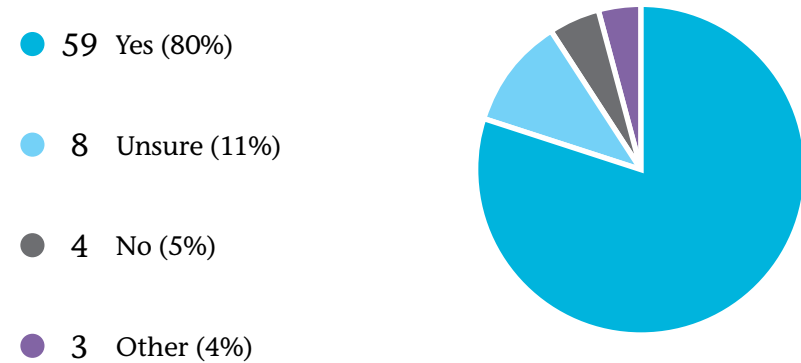
### Service Providers' Roles in their Organization



### Client Populations Primarily Worked With

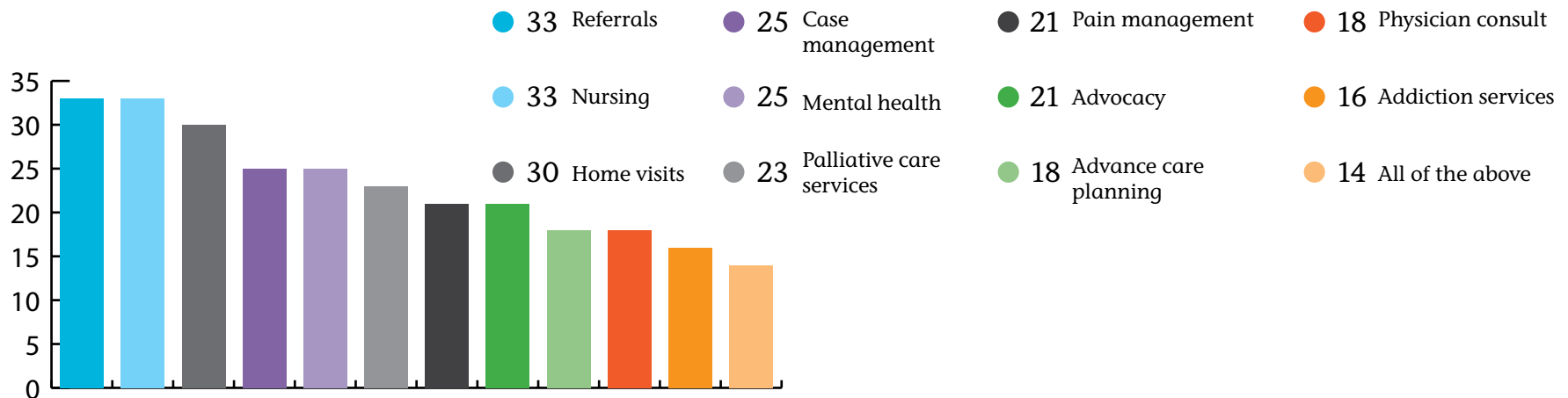


### Organizations of Employment that Provide Care for Advanced Chronic Disease

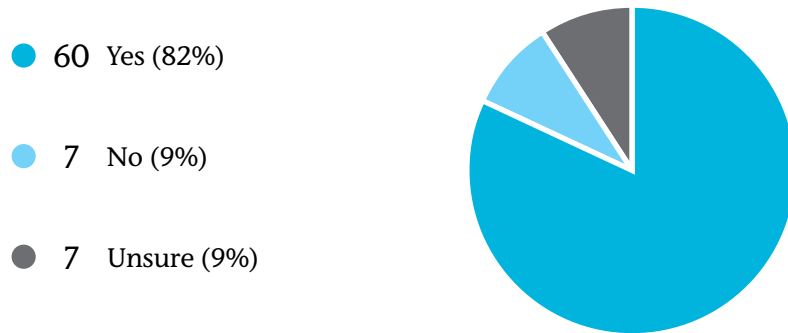


Those service providers who reported that their organization of employment does not provide care for those with advanced stage chronic disease were asked for their opinion on this. The most common reason for these services not being provided was a lack of funding or resources. Service providers noted that there is a lack of staff, that there is no specific professional who can provide this care, and that there is a lack of training and understanding, but they reported that they feel this service is important and needed.

### Types of Services Available for Palliative Care

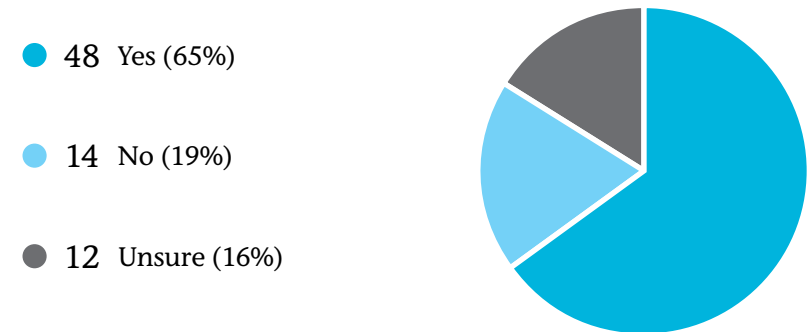


### Organizations of Employment that Provide Care for Advanced Chronic Disease in Vulnerably Housed or Homeless Patients



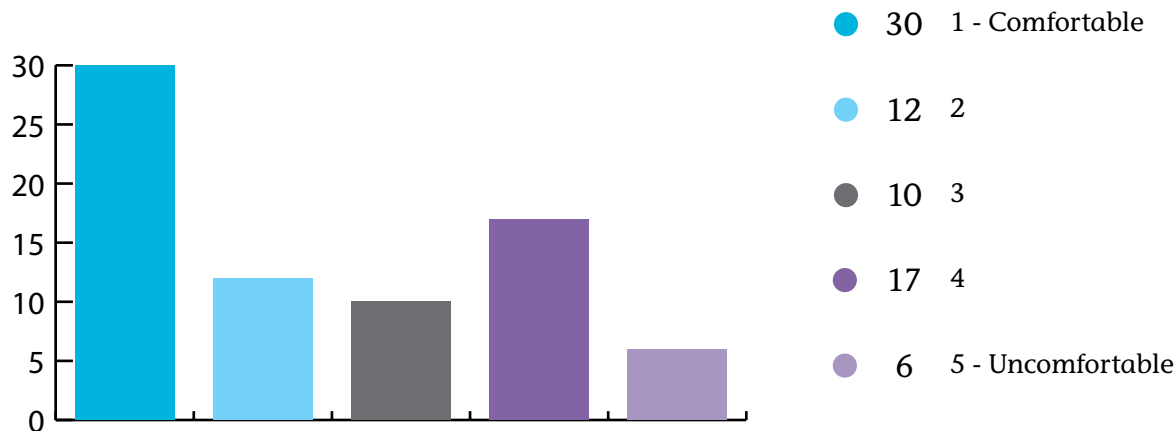
Service providers were asked to explain their response to this question and again, many noted that their organizations of employment probably would provide these services if they had the funding, training, or staff to do so. Service providers also explained that homeless clients with advanced chronic disease are often difficult to locate and assist with service provision, as they often want to stay out of the hospital as long as they can.

### Organizations of Employment that Provide Palliative Care



Service providers were invited to share additional information about the palliative care options at their place of employment and many reported that while their organizations of employment do not technically offer palliative care, they do assist when required as much as they are able to. Some also reported that their organizations of employment are now starting to offer palliative care. Also interesting to note was that homecare workers reported that in their experience, few clients can manage receiving end-of-life care at home due to limited resources available in homes. Additionally, homecare workers reported that in order to receive home care, the client has to have a fixed address, which often means that the care is being delivered to clients in the homes of their friends or family members.

### Comfort with Discussing Death and Dying with Patients



Service providers were asked when they feel that specialized care is needed for someone who is dying. The vast majority of service providers reported that palliative care should begin as soon as someone is diagnosed with a life-ending disease or as soon as the client feels they are ready to receive this care. Others also mentioned that specialized care is necessary when someone can no longer manage their activities of daily living, when their pain becomes unmanageable, or when the client's family is ready. Service users noted other factors that should be considered such as a client's age, their stage of illness, and whether their care can be managed with regular services. Individuals also felt that clients should be fully informed of this process; that supports should be used within the community where available; that this type of care requires constant assessment, planning, and intervention; that the person providing care should have specialized training; and finally, that this is a unique stage of life that requires its own care and attention.

Service providers were asked about barriers they perceive to accessing palliative and end-of-life care for vulnerably housed and or people living homeless and many barriers were identified. The most common barriers mentioned either directly or indirectly, was related to a lack of funding, resources, and staff. Access to housing and beds was another major barrier mentioned often. Service providers discussed things like a lack of housing, a lot of housing that is inadequate in that it is dangerous, dirty, or not wheelchair accessible for example, and that this inadequate housing leads to reluctance on the part of community supports to visit these places to provide care. Other things related to housing mentioned included long term care homes having long wait lists and hospitals not having enough beds.

While a lack of resources and housing concerns were the most common barriers reported, additional barriers were noted that coincided with these. Service providers reported that those who are vulnerably housed or homeless are difficult to remain in contact with due to not having an address and telephone number. This also means that clients can be difficult to schedule for appointments and remind of upcoming appointments. Some service providers noted this population is not always visible or easily identifiable in a community, which makes them difficult to assist. Many of these individuals are believed to experience stigma within the healthcare system due to their living situation and mental health difficulties such as stigma, which deters people from seeking help. Other barriers in this area were things like difficulty finding transportation, the distance required for travel to receive care, and the issue that palliative care is often not offered in remote communities, meaning that clients from these communities have to leave to receive services.

Another major barrier to receiving palliative care noted by many service providers was the issue of a lack of training and understanding with

healthcare professionals. Many believed, and heard from clients that there is a lack of trust with the healthcare system. It was reported that individuals had experienced many organizational issues such as difficulties with Health Canada. Additionally, many clients do not have primary care providers, some do not have Health Cards, and some are unaware of what services are available due to the complexity of our healthcare system. Service providers reported being unaware themselves of the resources that are available and that they are often unsure of where they can send clients for help.

Service providers were asked what would assist them in supporting clients in accessing palliative or end-of-life care services? The primary response was assistance with more palliative care training specific to the needs of those who are vulnerably housed or homeless, as well as training about spiritual and traditional care. Many service providers reported that better communication among health teams; greater awareness of available services; an increase in staffing, resources, and an overall increase in funding, would be beneficial to providing palliative care.

Other ideas service providers had included involved having a specific place to refer end-of-life clients for coordination of services; an increase in affordable housing, housing supports, and home care; more facilities with more beds; palliative care facilities that are not hospitals; mobile clinics and services that go to remote communities; an increase in public awareness through outreach services, pamphlets, and websites; pre-paid cell phones for clients in need; transportation; support groups; and more time to help these clients. Other recommendations that emerged included a place for culturally appropriate care, outreach sites, hospice care sites, and support services for family after family members pass away. Additionally, there is a need for assistance in navigating the healthcare system and a suggestion to relax the rules around who is eligible for services. It would also be helpful if information could be shared on how to access services and if the stigma within the system could be broken. Others suggested that this population and the public should be asked what they feel is necessary and that better overall communication and relationships are required.

Service providers were asked to discuss how their worldview or belief systems have served to empower or hinder the care they can provide or have provided to those who are homeless or vulnerably housed and many powerful themes emerged. The most common belief that emerged was a general belief that everyone has a right to care. Service providers believe that clients deserve to be treated with understanding, trust, compassion, respect, dignity, an open-mind, and without judgment. A humanist approach was mentioned as well as the importance of humour, sensitivity, and taking the time to listen. Service providers believed that clients should be met where they are in their journey and that no one should have to die alone. They believed that clients should be validated in their struggles, made to feel valuable, and to have their basic needs met. They believed that



clients should be allowed to choose where and how they die, and that all people deserve a place to live that feels like home.

Service providers reported it was important to advocate for vulnerable populations and to care for everyone to the best of their ability. They believed that it was important to help their communities. Additionally, many reported it is an honour to be able to be there for someone during their last weeks, months, and hours of life and that this type of care is a humbling experience.

Service providers were asked for recommendations on how to improve services for people who are homeless or vulnerably housed with advanced chronic disease and similar themes emerged. The most common recommendation was for easier access to services by providing things like transportation, mobile services, and case conferences.

Finally, service providers were invited to share additional comments. Various comments were made in this section, but most notable was the suggestion that people on the ground floor need to be making decisions regarding palliative care for this population. Additionally, service providers mentioned that racism, ageism, and classism needs to stop and that there is a desperate need for more long term care beds and more funding and resources.

## Coffee talk information exchange

The Project Coordinator arranged visits with the PAT Committee member contacts. This was done because of the limited time to establish meaningful relationships with people who work in this area. The contacts identified consisted of community social service and health care providers located in the North West LHIN. Email communication and phone calls were made in advance of visits. All health and social service providers were more than happy to meet in person and were happy to share their thoughts on the idea of homelessness, vulnerability, palliative care and what to do and not do. There was no obligation to meet with the Coordinator, however once they heard about the work being conducted most service providers offered their time during the Coordinator visit to their community. Due to the limited time of the project, the Coordinator arranged one on one meetings and group sessions to share the scope of the Project and open the discussion with the hope they would complete an online service provider survey, or assist in such a way as to ask their colleagues and peers to share their experiences in the survey.

Many of the providers agreed working with this population is complex, community-based solutions are necessary, and it is not a one size fits all approach to address the needs of either service user and/or provider. The providers noted it would be ideal to have someone who has lived experience be a part of forming solutions and recommendations for what might work. One provider stated, “They [people who live homeless] need to be humanized in order for people to care and to make this issue a priority”. This service provider stated it was how they began to realize this for themselves in their own practice.

In their own words, the work is arduous, time consuming and although rewarding it is also heartbreaking at times. Many stated they do not receive funding to do the work they do with the vulnerably housed and our people who live homeless. Much of the work they do with the target population is advocating and negotiating with service users to access health and social services to assist them. Many discussed the need for a trauma-based approach to care, exploring how to deal with intergenerational trauma, mental health and addictions, and adopting a humanistic approach, which meets people where they are. At the top of the list for all service providers was housing. They questioned how one could get better or begin to address their mental health, addictions, etc. without having the basic necessity of shelter.

Several discussions conflicted between health and social service providers. As one health care provider would state, end-of-life care or palliative care requires a medical model or environment and a social service provider would state anyone who is chronically homeless would not be happy or agree to a long term stay in a hospital and the best they could do would be to support them on the street or wherever they may be at the time. This remained the challenge when the Coordinator spoke with health care and social service providers.

# A Needs Assessment Report: Recommendations and Next Steps

**Equitable access to palliative care for the vulnerable and underserved populations in the North West LHIN region is an important concern, and action needs to be taken in a timely fashion to ensure the needs of our region are being met. Several recommendations emerged from both the service user and service provider portions of the survey results.**

**The following is a summary of recommendations and next steps that emerged:**

## 1. Continued Collaboration

It is imperative to develop and maintain a sustainable coordinated continuum of care to address holistic needs, traditional healing, and increase communication between health providers and social services, which will create opportunities to develop programs and services collectively. This can be accomplished through nurturing and maintaining an inclusive collaborative working relationship among stakeholders at every level.

Recommendations include:

- North West LHIN and Sub-Region Planning Tables
  - Create a means of communication and collaboration between health and social services providers to increase capacity and services for the target population.
    - Support the Regional Palliative Care Program (RPCP) to establish a working group to develop a more detailed plan/proposal to support the implementation of this report's recommendations.
    - Identify organizations and health care providers that will champion and identify the implementation priorities.
    - Ensure that individuals with lived experience of homelessness (service users) are meaningfully engaged in the development of further recommendations and any new programs and services targeted to them.
- Sub-Region Planning Tables review and incorporate this report's recommendations into their planning.

## 2. Funding and Resources

Advocate for increase in funding and resources directed toward developing integrated and organized services for the target population. The need for funding and resources was prominent throughout this survey. More funding is necessary to ensure the resources available can reach those in need and to ensure that the services and staff providing services are of the best quality possible.

Recommendations include:

- North West LHIN RPCP and its partners:

- Include a mechanism to access services for homeless and vulnerably housed individuals in the development of an Integrated Palliative Care Clinical Program while recognizing that this is a unique population that requires special attention and resources.
- Complete an inventory of organizations currently providing services to the homeless and vulnerably housed population in each sub-LHIN region.
- North West LHIN and North West LHIN RPCP:
  - Work with partners who provide lodging to explore the feasibility of creating community-based hospice-like spaces that would support the homeless and vulnerably housed at the end-of-life, both in the City of Thunder Bay and other LHIN Sub-regions.
- North West LHIN:
  - Fund dedicated health service delivery within social service organizations like emergency shelters and managed alcohol programs that are providing palliative care to homeless individuals who are dying.

## 3. Increase Access

Services need to be more easily available. Where services do exist, they are often not readily available to those without a fixed address and those without a health card or primary health care provider. As well, those located in remote communities have additional challenges to overcome when attempting to access services. It is also necessary to use current demographic data to prioritize the need for culturally appropriate and inclusive care. Adjustments are needed to allow this population access to services when required.

Recommendations include:

- North West LHIN:
  - Request that Health Service Providers track and report on the number of referrals received for individuals who have no fixed address, no Health Card, and/or no phone number. Report on the outcome of these referrals (e.g. was intake/assessment completed, was service provided, and was referring provider informed of referral outcome?).
- North West LHIN Home & Community Care:
  - Work with contracted service providers and other partners to develop a strategy to deliver home care services to individuals with no fixed address and/or no phone number.
  - Dedicate and develop services for people who live homeless, vulnerably housed and are marginalized.
  - Support access to all end-of-life care options, which includes palliative care and medical assistance in dying.

- Health and Social Service Providers:
  - Identify, examine, and address organizational barriers (e.g. policies & procedures, location/transportation, physical environment) that may prevent homeless and vulnerably housed individuals from accessing services.
- Ministry of Health & Long Term Care & Indigenous & Northern Affairs Canada
  - Collaboration between both levels of government to ensure equitable access to all government funded services whether on or off reserve.

#### 4. Eliminating Discriminatory Beliefs and Practices

Initiatives to address stigma are required in supporting the interface between service providers and service users. Stigma towards those who are homeless or vulnerably housed, specifically those challenged with addictions and related issues, was a topic that was frequently raised by both service users and providers. These changes begin with governmental agencies that determine who can receive services, following through to service providers who require a greater understanding of the issues facing this population, and to the public. Where possible, evidence-based approaches should be prioritized over approaches where evidence is preliminary, or lacking.

Recommendations and next steps include:

- North West LHIN RPCP and its partners:
  - Identify natural leaders within the homeless community in Thunder Bay and the region who could be recruited to assist with 1) the education of providers, and 2) engagement of the target population. A next step would involve expanding this pilot initiative to other communities.
- North West LHIN, North West LHIN RPCP, and Health and Social Service Providers:
  - Provide education to all staff on the lived experiences of the homeless and vulnerably housed and their challenges in accessing care.
  - Continue to support completion of recognized cultural safety training for service providers (e.g. San'yas Indigenous Cultural Safety).
  - Evaluate the need for ongoing cultural competence education and training within the North West LHIN region.

#### 5. Education for Service Providers

Health and social service providers could benefit from additional training in palliative care, advanced chronic disease, vulnerably housed and homeless populations, and Indigenous populations. Healthcare providers require an understanding of the unique issues these populations face when accessing care. Additionally, healthcare and social service providers could benefit from training on the types of services that are available to whom, and how these services can be accessed.

Recommendations and next steps include:

- Centre for Education and Research on Aging & Health (CERAH):
  - Plan a Lunch & Learn series on palliative care for homeless and vulnerably housed populations.
  - Increase awareness of palliative care education opportunities for service providers.

- Identify and inventory existing palliative care education programs for service providers working with the target population.
- Investigate evidence based practices in regards to competence education concerning the target population.
- North West LHIN:
  - Support the development of education relating to the target population in consultation and collaboration with those who have lived experience.

#### 6. Education for Service Users

Providing educational opportunities for the service user population is beneficial. The general sense emerging from service users was a lack of awareness of palliative care and the types of services that were available to them. This information should be readily available and easily accessible to service users so that they are able to find services when necessary. Using novel knowledge translation and dissemination approaches (e.g., health services survival guide) which actively engages those most likely to benefit from services will be important.

Recommendations include:

- North West LHIN RPCP and its partners:
  - Explore the feasibility of organizing a forum/conference for service users delivered by service users.
  - Identify natural leaders & helpers within the homeless community in Thunder Bay who could be recruited to assist with 1) the education of other service users, and 2) provide peer mentorship and support (i.e. model developed by the Champlain LHIN).
  - Determine key sites to disseminate information on available resources to the target population.
  - Ensure there is a plan for suggested strategies above.

#### 7. Housing First

Is an agreed approach that offers permanent, affordable housing as quickly as possible for individuals and families experiencing homelessness and in addition provides supportive services and connections to the community based-supports needed to retain housing.

Recommendations include:

- North West LHIN:
  - Adopt a housing first model.
- Regional and City District Social Services Board and/Ontario Aboriginal Housing
  - Review and improve access to subsidized housing for service users identified with palliative care needs.



# Limitations

Limitations noted within the project involved time constraints, the unique geographic composition of Northwestern Ontario, budget, and complexity of service providers and service users in regards to establishing relationships, linkages, and trust. Although there were limitations surrounding the Project, the majority of what PAT hoped to accomplish was achieved.

# Conclusion

This project has provided a preliminary glimpse of the vulnerable and underserved population, the barriers that they encounter, and the complexities involved navigating mainstream systems to accessing care. This needs assessment has demonstrated noticeable gaps within palliative care provision and access for this population. The information obtained from the service users and service providers has proven valuable in formulating feasible and practical recommendations for next steps in moving forward. Ultimately, this report speaks specifically to the necessity of immediate action that is required to provide compassionate care for all.





# References

- Boyden, J. Y., Curley, M. A., Deatrick, J. A., & Ersek, M. (2018). Review Article: Factors Associated With the Use of U.S. Community-Based Palliative Care for Children With Life-Limiting or Life-Threatening Illnesses and Their Families: An Integrative Review. *Journal Of Pain And Symptom Management*, 55117-131. doi:10.1016/j.jpainsymman.2017.04.017
- Buchan, L. (2018, February 05). Homeless people with terminal illnesses could be offered automatic right to housing. Retrieved from <https://www.independent.co.uk/news/uk/politics/homeless-illness-terminal-housing-right-parliament-ed-davey-liberal-democrats-a8191391.html>
- Canadian Mental Health Association. (2012). Getting Appropriate Personal and Professional Support (GAPPS) | CMHA Thunder Bay. Retrieved from <http://thunderbay.cmha.ca/programs-services/getting-appropriate-personal-and-professional-support-gapps/>
- Canadian Observatory on Homelessness. (2016). The State of Homelessness in Canada 2016. Retrieved from <http://homelesshub.ca/SOHC2016>
- CBC News. (2018a). Healthcare workers in Thunder Bay, Ont. bring medical care to the streets with a 'clinic on wheels' | CBC News. Retrieved from <http://www.cbc.ca/news/canada/thunder-bay/thunder-bay-outreach-van-1.4608653>
- CBC News. (2018b). Mental health workers, police officers working together under new crisis-response program | CBC News. Retrieved from <http://www.cbc.ca/news/canada/thunder-bay/joint-mobile-crisis-response-thunder-bay-1.4620777>
- Cipkar, C., & Dosani, N. (2016). The right to accessible healthcare: Bringing palliative services to Toronto's homeless and vulnerably housed population. *UBC Medical Journal*, 7(2), 19-20.
- City of Thunder Bay. (2016). Thunder Bay Point in Time Count Data 2016. Retrieved from <http://www.thunderbay.ca/Assets/Thunder+Bay+Point+In+Time+Data.pdf>
- CMA Policy. (2016). Palliative Care (pp. 1-8). Ottawa: Canadian Medical Association. Retrieved from <https://www.cma.ca/Assets/assets-library/document/en/advocacy/policy-research/cma-policy-palliative-care-pd16-01-e.pdf>
- Collier, R. (2011). Bringing palliative care to the homeless. *Canadian Medical Association Journal*, 183(6). doi:10.1503/cmaj.109-3756
- Declaration of Partnership and Commitment to Action, (2011). Advancing high quality, high value palliative care in ontario; A declaration of partnership and commitment to action [PDF]. Retrieved from [http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care\\_report.pdf](http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf)
- Department of Health and Community Services. (2018). Immunizations | Department of Health and Community Services. Retrieved March 09, 2018, from <http://www.health.gov.nl.ca/health/chronicdisease/cdcontrol.html>
- Department of Indigenous Services Canada. (2018, April 16). Indigenous Services Canada - Departmental Plan 2018-2019. Retrieved from <https://www.sac-isc.gc.ca/en/g/1523374573623/1523904791460#chp20>
- Dosani, N. (2016, May 09). What's a life worth? TEDxTalk [video file]. Retrieved April 05, 2018, from <https://www.youtube.com/watch?v=jcdm5fEqJmk>
- Expert Advisory Panel on Homelessness. (2016). A place to call home: Report of the Expert Advisory Panel On Homelessness. Retrieved from <http://www.mah.gov.on.ca/AssetFactory.aspx?did=11038>
- Fruch, V., Monture, L., Prince, H., & Kelley, M. L. (2016). Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care. *International Journal Of Indigenous Health*, 11(1), 50-74. doi:10.18357/ijih111201615303
- Health Canada. (2008). Fact Sheet - First Nations and Inuit Health Branch. Retrieved from <https://www.canada.ca/en/indigenous-services-canada/corporate/first-nations-inuit-health-branch/fact-sheet.html>
- Home and Community Care NWLHIN. (2017). Getting Started. Retrieved April 4, 2018, from <http://healthcareathome.ca/northwest/en/Getting-Care/getting-started>
- Homeless Hub. (2017). Thunder Bay. Retrieved March 29, 2018, from <http://homelesshub.ca/community-profiles/ontario/thunder-bay>
- Homelessness - The Facts. (2017). *New Internationalist*, (503), 18-19.
- Hospice Palliative Care Ontario. (2016). About Hospice Palliative Care. Retrieved March 15, 2018, from <http://www.hpcoc.ca/who-we-are/about-hospice-palliative-care/>
- Hudson, B. F., Flemming, K., Shulman, C., & Candy, B. (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care*, (1), doi:10.1186/s12904-016-0168-6
- Inner City Health Associates (ICHA). (n.d.). PEACH. Retrieved April 05, 2018, from <http://www.icha-toronto.ca/programs/peach>
- Jaworsky, D., Gadermann, A., Duhoux, A., Naismith, T. E., Norena, M., To, M. J., & ... Palepu, A. (2016). Residential Stability Reduces Unmet Health Care Needs and Emergency Department Utilization among a Cohort of Homeless and Vulnerably Housed Persons in Canada. *Journal Of Urban Health*, (4), 666. doi:10.1007/s11524-016-0065-6

Kauppi, C., O'Grady, B., Schiff, R., Martin, F., & Ontario Municipal Social Services Association. (2017). Homelessness and hidden homelessness in rural and northern Ontario. Guelph, ON: Rural Ontario Institute.

Kirkness, V. J., & Barnhardt, R. (2016). First Nations and Higher Education: The Four R's--Respect, Relevance, Reciprocity, Responsibility. *Journal Of College And University Student Housing*, 42(2), 94-109.

Lee, J. (2017). Mobile team helps Calgary's homeless die with dignity | CBC News. Retrieved March, 20, 2018 from <http://www.cbc.ca/news/canada/calgary/palliative-care-calgary-homeless-1.3966695>

Leung, A. K., Nayyar, D., Sachdeva, M., Hwang, S. W., & Song, J. (2015). Chronically homeless persons' participation in an advance directive intervention: A cohort study. *Palliative Medicine*, 29(8), 746-755.

Lewis, J. M., DiGiacomo, M., Currow, D. C., & Davidson, P. M. (2011). Review Article: Dying in the Margins: Understanding Palliative Care and Socioeconomic Deprivation in the Developed World. *Journal Of Pain And Symptom Management*, 42105-118. doi:10.1016/j.jpainsymman.2010.10.265

Local Health Integration Network. (2014). First Nations by LHIN [PDF]. Retrieved March 12, 2018, from [www.lhins.on.ca/~media/Pan-LHIN%20Content/Provincial%20Aboriginal%20LHIN%20Network/Aboriginal\\_FirstNations\\_Ontario\\_WithNames.pdf?la=en](http://www.lhins.on.ca/~media/Pan-LHIN%20Content/Provincial%20Aboriginal%20LHIN%20Network/Aboriginal_FirstNations_Ontario_WithNames.pdf?la=en)

Local Health Integration Network. (n.d.a). Aboriginal health services map [PDF]. Retrieved March 12, 2018, from [www.lhins.on.ca/~media/Pan-LHIN%20Content/Provincial%20Aboriginal%20LHIN%20Network/Aboriginal%20health%20services%20map.pdf?la=en](http://www.lhins.on.ca/~media/Pan-LHIN%20Content/Provincial%20Aboriginal%20LHIN%20Network/Aboriginal%20health%20services%20map.pdf?la=en)

Local Health Integration Network. (n.d.b). About the North West LHIN. Retrieved March 27, 2018, from <http://www.northwestlhins.on.ca/AboutOurLHIN.aspx>

Local Health Integration Network. (2015a). North west lhins population profile. [PDF]. Retrieved from, [www.northwestlhins.on.ca/~media/sites/nw/reports/Population%20Health%20Profiles/Population\\_Profile\\_December-2015.pdf?la=en](http://www.northwestlhins.on.ca/~media/sites/nw/reports/Population%20Health%20Profiles/Population_Profile_December-2015.pdf?la=en)

Local Health Integration Network. (n.d.c). Sub-regions in the North West LHIN: The Right Care, When and Where it's Needed. Retrieved March 29, 2018, from [http://www.northwestlhins.on.ca/AboutOurLHIN/LHIN\\_Sub-regions.aspx](http://www.northwestlhins.on.ca/AboutOurLHIN/LHIN_Sub-regions.aspx)

McNeil, R., Guirguis-Younger, M., & Dille, L. B. (2012). Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals. *BMC Palliative Care*, 11(1). doi:10.1186/1472-684x-11-14

Mikkonen, J., & Raphael, D. (2010). Social determinants of health. [electronic resource] : the Canadian facts. Toronto, Ont.: York University School of Health Policy and Management, 2010 (Saint-Lazare, Quebec: Gibson Library Connections, 2010).

Ministry of Health and Long-Term Care. (2016). Palliative and End-Of-Life Care Provincial Roundtable Report: A Report from Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care. Toronto: Author.

NorWest Community Health Centres. (n.d.). Outreach Locations. Retrieved April 24, 2018, from <http://www.norwestchc.org/locations/thunder-bay/walk-clinics>

NorthWesthealthline. (n.d.). North West Local Health Integration Network - Home and Community Care. Retrieved April 04, 2018, from <http://www.northwesthealthline.ca/displayService.aspx?id=140806>

NorthWesthealthline. (2017). Sioux Lookout - Front St - Wellness and Recovery Centre. Retrieved April 02, 2018, from <http://www.northwesthealthline.ca/displayService.aspx?id=141680>

NorthWesthealthline. (2018). Street Outreach Nursing. Retrieved April 02, 2018, from <http://www.northwesthealthline.ca/displayService.aspx?id=141242>

North West LHIN. (2014). Regional palliative care plan [PDF]. Retrieved from [http://www.sjcg.net/documents/research/projects/nwlhin-rpcp/reports/regional/North%20West%20LHIN%20Regional%20Palliative%20Care%20Plan%20\(English\).pdf](http://www.sjcg.net/documents/research/projects/nwlhin-rpcp/reports/regional/North%20West%20LHIN%20Regional%20Palliative%20Care%20Plan%20(English).pdf)

North West LHIN. (n.d.). Local Health Hub Profiles. Retrieved April 2, 2018, from <http://www.northwestlhins.on.ca/goalsandachievements/Health%20Services%20Blueprint/BlueprintTools/LocalHealthHubProfiles.aspx>

Ontario Aboriginal Housing Services. (2016). First Nations, Métis, and Inuit Urban and Rural Homelessness Policy Statement. Retrieved from, <http://www.ontarioaboriginalhousing.ca/wp-content/uploads/2016/08/OAHS-FNMI-Homelessness-Policy-Statement-Final.pdf>

Ontario Hospital Association. (2015). Rural health hubs framework for Ontario [PDF]. Toronto, Ontario. Retrieved from <https://www.oha.com/Documents/Rural%20Health%20Hub%20Framework%20Ontario.pdf>

Ontario Palliative Care Network. (n.d.). Ontario Palliative Care Network Action Plan 1: 2017 – 2020 Action Areas, Actions and Timelines [PDF]. Retrieved May 4, 2018, from <https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNActionPlan1.pdf>

Oxford University Press. (2018). Life-limiting | Definition of life-limiting in US English by Oxford Dictionaries. Retrieved March 19, 2018, from <https://en.oxforddictionaries.com/definition/us/life-limiting>



Schuurman, N., Martin, M., Crooks, V. A., & Randall, E. (2018). The development of a spatial palliative care index instrument for assessing population-level need for palliative care services. *Health And Place*, 4950-58. doi:10.1016/j.healthplace.2017.11.004

Shelter House Thunder Bay. (2018). Shelter House Thunder Bay - Kwaie Kii Win Managed Alcohol Centre. Retrieved from <http://www.shelterhouse.on.ca/article/kwaie-kii-win-managed-alcohol-centre-497.asp>

Shelter House Thunder Bay. (2018). Shelter House Thunder Bay - A little bit of caring goes a long way. Retrieved from <http://www.shelterhouse.on.ca/>

Statistics Canada. (2016a). CANSIM Table 278-0016, homeless shelter capacity, bed and shelter counts for emergency shelters, transitional housing and violence against women shelters for Canada and provinces, Employment and Social Development Canada. Retrieved from <http://www5.statcan.gc.ca/cansim/a26?lang=eng&retrLang=eng&id=2780016&pattern=&stByVal=1&p1=1&p2=1&tabMode=dataTable&csid=>

Statistics Canada. (2016b). Insights on Canadian Society Hidden homelessness in Canada. Retrieved from <http://www.statcan.gc.ca/pub/75-006-x/2016001/article/14678-eng.htm>

Statistics Canada. (2017). The housing conditions of Aboriginal people in Canada [PDF]. Retrieved from <http://www12.statcan.gc.ca/census-recensement/2016/as-sa/98-200-x/2016021/98-200-x2016021-eng.pdf>

St. Clare Hospice. (n.d.). What does that mean? Retrieved March 9, 2018, from <https://stclarehospice.org.uk/what-does-that-mean/>

St. Joseph's Care Group. (n.d.). Getting Appropriate Personal & Professional Supports (GAPPS) Program. Retrieved April 23, 2018, from [http://www.sjcg.net/services/mental-health\\_addictions/outpatient/gapps.aspx](http://www.sjcg.net/services/mental-health_addictions/outpatient/gapps.aspx)

St. Joseph's Care Group. (2018). Palliative care current state snapshot January 2018.

Strong, G. (2015). Northern Ontario Medical Journal » Compass North combines service, education, outreach. Retrieved from <http://www.nomj.ca/2015/06/12/compass-north-combines-service-education-outreach.html>

Sumalinog, R., Hwang, S. W., Harrington, K., & Dosani, N. (2017). Advance care planning, palliative care, and end-of-life care interventions for homeless people: A systematic review. *Palliative Medicine*, 31(2), 109-119.

The Constitution Act, 1982, Schedule B to the Canada Act 1982 (UK), 1982, c 11. Retrieved May 3, 2018, from <<http://canlii.ca/t/ldsx>>

The Research Alliance for Canadian Homelessness, Housing, and Health (REACH 3). (2010). Housing Vulnerability and Health: Canada's Hidden Emergency. Retrieved from <http://www.stmichaelshospital.com/pdf/crich/housing-vulnerability-and-health.pdf>

Thistle, J. (2017.) *Indigenous Definition of Homelessness in Canada*. Toronto: Canadian Observatory on Homelessness Press.

Truth and Reconciliation Commission of Canada. (2015). Truth and Reconciliation Commission of Canada: Calls to Action [PDF]. Retrieved from, [http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls\\_to\\_Action\\_English2.pdf](http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English2.pdf)

Waisel, D. B. (2013). Vulnerable populations in healthcare. Retrieved March 19, 2018, from <https://insights.ovid.com/crossref?an=00001503-201304000-00015>

# Appendices

## Appendix A

### Palliative Care for Vulnerable and Underserved Populations Partnership Advisory Team August 2017

#### Terms of Reference

##### Background

The government is seeking better care for Ontarians at end-of-life. A multi-stakeholder report, A Declaration of Partnership and Commitment to Action was developed in 2011 to outline a vision for palliative care in Ontario. In 2016 the Palliative and End-of-Life Care Provincial Report was tabled and captures discussions from invested stakeholders in Ontario around palliative care and provides observations and key elements to successful palliative care models. One of the key findings from this report was the number of Ontarians who face additional barriers to accessing appropriate palliative and end-of-life services, particularly people who are vulnerably housed or live homeless.

As a result of this work the Minister announced the launch of a new Ontario Palliative Care Network (OPCN). The OPCN is a partnership of community stakeholders and health system planners who are developing a coordinated standardize approach for delivering palliative care services in the province. OPCN will support regional implementation of high quality and high value palliative care and act as the Ministry's principal advisor to palliative care, drive quality improvements, and monitor system-level performance.

##### Purpose

The Partnership Advisory Team will facilitate and support the development and implementation of the Palliative Care for Vulnerable and Underserved Populations project within the NW LHIN.

##### Mandate

To complete and needs assessment on the needs of palliative care for vulnerable and underserved populations in the NW LHIN.

##### Objectives

1. Establish a Partnership Advisory Team
  - Identify, engage and consult with various stakeholders across the region including social service and health providers not initially engaged.
  - Guide the development and execution of the project
2. Conduct a community needs assessment to improve understanding of current state of palliative care services for people who live homeless and explore innovative models that can address the care needs of homeless people living in urban, rural and remote communities.
  - Develop a needs assessment plan including clear identification of target population
  - Gather qualitative and quantitative data
  - Identify and prioritize needs and gaps
  - Link to promising practices provincially and nationally to inform planning and executing of the needs assessment

3. Create and share a final report outlining recommendations on palliative care service provision to the vulnerably housed or people living homeless population
  - Develop recommendations to address identified needs, gaps, and priorities including resource requirements for implementing recommendations.
  - Disseminate results of the report with local partners and broader audience
  - Inform future planning at individual organizational and regional program level.

## Membership

Membership will include community organizations listed in the proposal and any additional members will be added as agreed upon by the PAT.

PAT will meet approximately three to four times through the duration of the project. The project concludes, March 31, 2018. Meetings will take place in person or by teleconference.

## Committee Lead & Representation

The committee will be comprised of a representative or designate from organizations/programs which palliative care, vulnerably housed or people who live homeless are within their mandate.

This includes but is not limited to:

1. Dilico Anishinabek Family Care, Lead
2. Centre for Education Research on Aging and Health
3. Hospice Northwest
4. Lakehead University, School of Social Work
5. NorWest Community Health Centres
6. North West Local Health Integration Network
7. Regional Indigenous Cancer Lead
8. Regional Cancer Centre
9. Regional Palliative Care Program
10. Thunder Bay Regional Health Science Palliative Care Physicians

11. Shelter House
12. Wequedong Lodge
13. William Bill George Extended Care Unit

## Decision-making

Decisions will be made by consensus.

Quarterly reports will be distributed to the entire committee. A final report will be disseminated to the Ministry of Health and Long Term Care at the end of the fiscal year.

## Frequency of Meetings

Meetings will be held every other month for the duration of the project. Additional meetings may be called as they are required.

## Minutes

Minutes will be circulated to the members prior to the meeting,

## Reporting

In collaboration with the PAT, the Lead will provide quarterly progress reports and a final report to on the community needs assessment outcome.

## Conflict of Interest

Members should perform in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Both the appearance of conflict, as well as actual conflict, is to be avoided. When members believe they have a conflict of interest that will prevent them from reaching an impartial decision, they must declare a conflict of interest to the Committee and withdraw themselves from the discussion and/or activity.

# Appendix B

## Six Step Process Utilized for the Project

### Step 1: Identify and Engage Stakeholders

The Partnership Advisory Team;

- The original people who supported and participated in writing the proposal for this project were invited to participate on the committee called the Partnership Advisory Team (PAT).
- Agreed to a meeting schedule, which included monthly meetings in person and via teleconference.
- PAT developed and agreed upon a Terms of Reference to guide the work and collaboration.
- Discussed and invited a community member with lived experience in living homeless or vulnerably housed to participate on the committee to inform the process.
- Explored ways to reach the identified target population in the city and region.
- A list of service users working with the target population was established with the support of the Centre for Research Aging & Health and the North West LHIN Ontario Regional Palliative Care Program.
- Held first meetings to begin planning process.

### Step 2: Define Target Populations

The Partnership Advisory Team;

- Discussed and explored how to define the target population.
- Suggested several individuals, groups, and organizations who work with the target population to initiate linkages and relationships.
- Contact was made with a team in British Columbia to inquire as to how they developed their surveys for service users and providers.
- An invitation to participate was sent to several Indigenous led and governed organizations who work with the target population.

- Meetings were set up with responding organizations to provide project information as well as ask for feedback and input to the project. Due to limited time, staff and resources some did not want to participate as a PAT committee member but did share their thoughts.
- A survey for service users and service providers was drafted and circulated for review.

A community travel schedule was drafted and circulated.

### Step 3: Collect & Analyze Data

The Partnership Advisory Team

- The Project Coordinator reached out to health and social service providers to set up phone calls or in person meetings to discuss the Project objectives, goals and desired outcome.
- Met with an individual with lived experience to discuss the project and explore ways in which to gain a clear understanding of what is occurring to improve services and care for the target population.
- Met with local researcher who completed a recent research project on Northwestern Ontario specifically to understand how information was collected.
- The Project Coordinator visited Red Lake, Sioux Lookout, Pays Platt, Pic Moberg, as well as Red Rock First Nation and met with service providers to discuss the project. All service providers offered to share the survey with service users in their community. One organization, which had a close working relationship with a remote First Nation, offered to, and did take the service user survey to that community for completion.
- Service providers completed surveys in the Rainy River sub-region. Service user surveys were not completed due to limited travel time.

- Service user data were collected through paper and pencil survey format. This data was manually entered into an Excel spreadsheet. Service provider data were collected electronically via Survey Monkey. These data were pulled into an Excel spreadsheet. Descriptive statistics were calculated in Excel by quantifying survey responses. Graphical images were created to display the results.
- As a part of a larger network of peers working on projects across Ontario, the Project Coordinator joined the Ontario Palliative Care Network Knowledge Sharing Forum to connect with other LHIN funded Palliative Care projects in Ontario doing similar and like minded work.
- Project Coordinator attended the CERAH Palliative Care Booster; “Let’s Talk About It: Conversations worth Having to explore the area of palliative care and marginalized populations”.
- The Project Coordinator, on behalf of PAT, submitted an abstract to present preliminary findings to the Hospice Palliative Care Ontario Conference in Toronto.

## Step 4: Validate & Prioritize Findings

The Partnership Advisory Team

- Survey findings were reviewed in PAT meetings.
- The Project parameters were limited by time, budget and geography, and as a result representation from each LHIN sub-region was not completely achieved.
- The Final Report includes commentary from roundtable discussions with service providers and service users (see Coffee Talk and Information Exchange).

## Step 5: Document and Communicate

The Partnership Advisory Team

- Several drafts of the final report were shared with PAT.
- PAT met on two occasions to review and in addition communicated by telephone and email with suggestions and feedback.
- The Project Coordinator reached out to committee members who were not in attendance to discuss their feedback and input.

- When speaking with local and regional stakeholders not affiliated with the Project, the idea of the Project was well received. Groups, organizations and individuals were pleasantly surprised about the idea of an investment in palliative care for underserved and vulnerable populations.
- The Project Coordinator informed the committee members that service providers perceived and identified stakeholders and people with lived experience as ideal advocates and foundations for grassroots initiatives for people who live homeless and suffer from life-limiting illnesses since they are passionate, committed, and living in this reality every day.

## Step 6: Final Report and Recommendation

The Partnership Advisory Team

- The Partnership Advisory Team met on two occasions to review the 1st and 2nd draft. Feedback was received and edits incorporated.
- Preliminary findings of the needs assessment were presented at the Hospice Palliative Care Ontario Forum in Toronto on Sunday April, 22, 2018. Approximately 12 people were in attendance.
- In future the Centre for Research on Aging & Health will host the Northwestern Ontario Palliative Care Conference, Oct 24-26, 2018 and Dilico Anishinabek Family Care as the lead agency has been asked to submit an abstract to participate. This request is being considered.
- The final report will be emailed to all Stakeholders who participated in the Project.

# Appendix C

## A Needs Assessment on Palliative Care for Vulnerable and Underserved Populations

### SERVICE USER

Interviewer: \_\_\_\_\_

Date and Time: \_\_\_\_\_

Location: \_\_\_\_\_

Sub-LHIN Region \_\_\_\_\_

### Demographic Questions

1. I understand my answers will be confidential and all information collected will be used to make recommendations to health care, social service providers and government regarding palliative care and end-of-life care for people who live homeless and are vulnerably housed. ☐ Yes ☐ No
2. What gender do you identify with?  
☐ Male ☐ Female ☐ Transgender ☐ Prefer not to answer
3. How old are you?  
☐ Under 18 ☐ 26-35 ☐ 46-55 ☐ 66+  
☐ 19-25 ☐ 36-45 ☐ 56-65 ☐ Prefer not to answer
4. What do you identify as your race or ethnicity?  
☐ White (Caucasian) ☐ Asian/Pacific Islander ☐ Black/African/Canadian ☐ Other \_\_\_\_\_  
☐ Aboriginal (First Nation, Metis & Inuit) ☐ East Indian ☐ Hispanic/Latino ☐ Prefer not to answer
5. What language do you speak at home?  
☐ English ☐ Ojibway ☐ Oji-Cree ☐ Italian ☐ Prefer not to answer  
☐ French ☐ Cree ☐ Finnish ☐ Other \_\_\_\_\_



6. What is the highest level of education you completed?

- |   |  |  |   |
|---|--|--|---|
| <input type="checkbox"/> Elementary School    | <input type="checkbox"/> Middle School           | <input type="checkbox"/> Attended University | <input type="checkbox"/> Post-Graduate Degree |
| <input type="checkbox"/> Some High School     | <input type="checkbox"/> Some College (Trade)    | <input type="checkbox"/> University Degree   | <input type="checkbox"/> Other _____          |
| <input type="checkbox"/> High School Graduate | <input type="checkbox"/> College Diploma (Trade) | <input type="checkbox"/> Some University     | <input type="checkbox"/> Prefer not to answer |

7. What is your current marital status?

- |  |  |   |
|--|--|---|
| <input type="checkbox"/> Single                | <input type="checkbox"/> Widowed               | <input type="checkbox"/> Other _____          |
| <input type="checkbox"/> Married or common law | <input type="checkbox"/> Divorced or Separated | <input type="checkbox"/> Prefer not to answer |

8. Where are you living now? Or in the past year? (Select all that apply).

- |  |  |  |   |
|--|--|--|---|
| <input type="checkbox"/> Emergency shelter                     | <input type="checkbox"/> Couch surfing             | <input type="checkbox"/> Social housing      | <input type="checkbox"/> Purchased house (home ownership) |
| <input type="checkbox"/> Outdoors/Streets                      | <input type="checkbox"/> Domestic violence shelter | <input type="checkbox"/> Vehicle             | <input type="checkbox"/> Detoxification or therapy center |
| <input type="checkbox"/> Public Building/Abandoned Building    | <input type="checkbox"/> Rental Unit               | <input type="checkbox"/> Camping/tenting     | <input type="checkbox"/> Other _____                      |
| <input type="checkbox"/> Makeshift shelter or tent on the land | <input type="checkbox"/> With family/friends       | <input type="checkbox"/> Mobile home/trailer | <input type="checkbox"/> Prefer not to answer             |

9. Do you feel safe there? ☐ Yes ☐ No

## Income Related Questions

10. Which of the following ways do you earn an income? (Select all that apply).

- |  |   |  |   |   |
|--|---|--|---|---|
| <input type="checkbox"/> Full Time Employment                      | <input type="checkbox"/> Old Age Pension      | <input type="checkbox"/> Prostitution      | <input type="checkbox"/> Drug Dealing                   | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Part Time Employment                      | <input type="checkbox"/> Employment Insurance | <input type="checkbox"/> Theft/Shoplifting | <input type="checkbox"/> Ontario Work/Social Assistance |   |
| <input type="checkbox"/> Ontario Disability Support Program (ODSB) | <input type="checkbox"/> Selling Goods        | <input type="checkbox"/> Panhandling       | <input type="checkbox"/> Other (Please specify) _____   |   |

11. How much money do you make a month? \_\_\_\_\_

## Health Related Questions

12. Do you have an Ontario Health Card? ☐ Yes ☐ No ☐ Lost ☐ Prefer not to answer

13. Do you have a family doctor? ☐ Yes ☐ No      Type: (i.e. doctor, nurse practitioner, other)

14. Have you been diagnosed with or treated for any of the following health conditions? (Check all that apply)

- |                                       |                                      |   |  |   |
|---------------------------------------|--------------------------------------|---|--|---|
| <input type="checkbox"/> Arthritis    | <input type="checkbox"/> Addictions  | <input type="checkbox"/> Heart Disease (stroke) | <input type="checkbox"/> PTSD                                  | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Cancer (Any) | <input type="checkbox"/> Hepatitis C | <input type="checkbox"/> Mental Health          | <input type="checkbox"/> Bipolar                               |   |
| <input type="checkbox"/> Dementia     | <input type="checkbox"/> HIV/AIDS    | <input type="checkbox"/> Depression             | <input type="checkbox"/> Chronic Obstructive Pulmonary Disease |   |
| <input type="checkbox"/> Diabetes     | <input type="checkbox"/> Asthma      | <input type="checkbox"/> Schizophrenia          | <input type="checkbox"/> Other (Please specify)_____           |   |

15. Have you had any of the following health challenges in the past year? (Check all that apply)

- |  |   |  |  |
|--|---|--|--|
| <input type="checkbox"/> Heart Attack                | <input type="checkbox"/> Traumatic Injury | <input type="checkbox"/> Cancer (Type:_____) | <input type="checkbox"/> Other (Please specify)_____ |
| <input type="checkbox"/> Diabetes                    | <input type="checkbox"/> Kidney Disease   | <input type="checkbox"/> Heart Disease       | <input type="checkbox"/> Prefer not to answer        |
| <input type="checkbox"/> Injection Related Infection | <input type="checkbox"/> COPD             | <input type="checkbox"/> Pneumonia           |  |
| <input type="checkbox"/> Stroke                      | <input type="checkbox"/> Brain Injury     | <input type="checkbox"/> Mental Health       |  |

16. If you were sick, where would you go for help?

---

---

---

17. Do you go for regular health checkups? If yes, where? (Check all that apply)

- |                                     |   |   |   |
|-------------------------------------|---|---|---|
| <input type="checkbox"/> I don't go | <input type="checkbox"/> Walk-in Clinic     | <input type="checkbox"/> Emergency Room | <input type="checkbox"/> Other _____          |
| <input type="checkbox"/> Doctor     | <input type="checkbox"/> Family Health Team | <input type="checkbox"/> Nurse          | <input type="checkbox"/> Prefer not to answer |

18. In the past year have you stayed overnight in a hospital?

- ☐ Yes   ☐ No   ☐ Prefer not to answer

If yes, what was the reason for your most recent hospitalization? \_\_\_\_\_  
\_\_\_\_\_

19. How many times have you been to emergency in the last year?

- ☐ 1-5 times   ☐ 6-10 times   ☐ 11-15 times   ☐ 16 or more times   ☐ Prefer not to answer

20. Are you comfortable talking about your health conditions?   ☐ Yes   ☐ No   ☐ Prefer not to answer

21. Are you comfortable talking about death and dying?   ☐ Yes   ☐ No   ☐ Prefer not to answer

22. Who do you turn to when you are sick?

---

---

23. Do you face any challenges accessing health services? (Check all that apply)

- |   |  |   |   |
|---|--|---|---|
| <input type="checkbox"/> Services Are Not Available | <input type="checkbox"/> Racism/Discrimination         | <input type="checkbox"/> Transportation                       | <input type="checkbox"/> Do not know what is available  |
| <input type="checkbox"/> Financial Barriers         | <input type="checkbox"/> Previous Negative Experiences | <input type="checkbox"/> Admission Criteria (i.e. no address) | <input type="checkbox"/> Do not have access to services |
| <input type="checkbox"/> A Valid Health Card or ID  | <input type="checkbox"/> Childcare                     | <input type="checkbox"/> Feel Inferior or Less Than           | <input type="checkbox"/> Other _____                    |
|   |  |   | <input type="checkbox"/> Prefer not to answer           |

24. In your opinion how can health services change to meet your needs?

---

---

25. Does the health provider's ethnic or racial background, age, gender or membership in your community matter to you when receiving care or services? Please explain.

---

26. How many people do you know who have died in the last 2 years? Were they receiving the care they needed before they died? If not, what did they need that they weren't receiving?

---

---

---

27. If you were diagnosed with a life-threatening illness or knew you were dying, what would be most important to you?

---

---

---

28. Do you have any suggestions for providing care for people facing life threatening illnesses?

---

---

---

**Thank you for your time.**

# Appendix D

## Needs Assessment on Palliative Care for Vulnerable and Underserved Populations

### SERVICE PROVIDERS

Interviewer: \_\_\_\_\_  
Date and Time: \_\_\_\_\_  
Location/Community: \_\_\_\_\_  
Sub-LHIN Region \_\_\_\_\_

### Demographic Questions

1. I understand my answers will be confidential and all information collected will be used to make recommendations to government regarding end-of-life care for people who live homeless and are vulnerably housed. ☐ Yes ☐ No
2. What gender do you identify with?  
☐ Male ☐ Female ☐ Transgender ☐ Prefer not to answer
3. How old are you?  
☐ 19-25 ☐ 36-45 ☐ 56-65 ☐ Prefer not to answer  
☐ 26-35 ☐ 46-55 ☐ 66+
4. What do you identify as your race or ethnicity?  
☐ White (Caucasian) ☐ Asian/Pacific Islander ☐ Black/African/Canadian ☐ Other \_\_\_\_\_  
☐ Aboriginal (First Nation, Metis & Inuit) ☐ East Indian ☐ Hispanic/Latino ☐ Prefer not to answer
5. What language do you speak at home?  
☐ English ☐ Ojibway ☐ Oji-Cree ☐ Italian ☐ Prefer not to answer  
☐ French ☐ Cree ☐ Finnish ☐ Other \_\_\_\_\_

6. What is the highest level of education you completed?

- |  |  |  |   |
|--|--|--|---|
| <input type="checkbox"/> Elementary School or less | <input type="checkbox"/> Middle School           | <input type="checkbox"/> Attended University | <input type="checkbox"/> Post-Graduate Degree |
| <input type="checkbox"/> Some High School          | <input type="checkbox"/> Some College (Trade)    | <input type="checkbox"/> University Degree   | <input type="checkbox"/> Other _____          |
| <input type="checkbox"/> High School Graduate      | <input type="checkbox"/> College Diploma (Trade) | <input type="checkbox"/> Some University     | <input type="checkbox"/> Prefer not to answer |

7. In your formal education did you receive training or education specific to palliative care or end-of-life care? If so, please explain.

---

---

---

## Organization Demographic

8. Which sector best represents your organization? Select all that apply.

- |   |  |   |  |
|---|--|---|--|
| <input type="checkbox"/> Hospital/healthcare provider | <input type="checkbox"/> Education                               | <input type="checkbox"/> Social Services            | <input type="checkbox"/> Home & Community Care       |
| <input type="checkbox"/> Emergency department         | <input type="checkbox"/> First Nation, Metis, Inuit Organization | <input type="checkbox"/> Mental Health & Addictions | <input type="checkbox"/> Private Practitioner        |
| <input type="checkbox"/> Primary Care Clinic          | <input type="checkbox"/> First Nation Nursing Station            | <input type="checkbox"/> Community Coalition        | <input type="checkbox"/> Other (Please specify)_____ |

9. In your estimation, what population of client/patient do you primarily work with? Select all that apply.

- |   |   |   |   |
|---|---|---|---|
| <input type="checkbox"/> White (Caucasian)                        | <input type="checkbox"/> Asian/Pacific Islander | <input type="checkbox"/> Black/African/Canadian | <input type="checkbox"/> Other _____          |
| <input type="checkbox"/> Aboriginal (First Nation, Metis & Inuit) | <input type="checkbox"/> East Indian            | <input type="checkbox"/> Hispanic/Latino        | <input type="checkbox"/> Prefer not to answer |

10. What is your role in your organization or program? Select one response that best describes your role

- |   |   |  |   |
|---|---|--|---|
| <input type="checkbox"/> Manager                      | <input type="checkbox"/> Social Worker/Social Service Worker  | <input type="checkbox"/> Community Health Representative | <input type="checkbox"/> Physician                      |
| <input type="checkbox"/> Program/Project Coordinator  | <input type="checkbox"/> Outreach/Support Worker              | <input type="checkbox"/> Nurse Practitioner              | <input type="checkbox"/> Family Support                 |
| <input type="checkbox"/> Nurse in Charge              | <input type="checkbox"/> Harm Reduction Worker                | <input type="checkbox"/> Health Director                 | <input type="checkbox"/> Other Health Care Professional |
| <input type="checkbox"/> Nurse/Community Health Nurse | <input type="checkbox"/> Personal Support/Home Support Worker | <input type="checkbox"/> Allied Health Practitioner      | (Please specify)_____                                   |

11. How many years have you worked in your professional role? \_\_\_\_\_

12. Does your organization provide palliative care and end-of-life care to people who are living homeless or vulnerably housed?

---

---

---

13. Does your organization provide care for advanced chronic diseases? ☐ Yes ☐ No ☐ Unsure

14. If yes, what services are provided? Select all that apply.

- |  |  |   |   |
|--|--|---|---|
| <input type="checkbox"/> Referrals             | <input type="checkbox"/> Case management   | <input type="checkbox"/> Home visits              | <input type="checkbox"/> Advocacy           |
| <input type="checkbox"/> Advance care planning | <input type="checkbox"/> Physician consult | <input type="checkbox"/> Palliative Care Services | <input type="checkbox"/> Addiction Services |
| <input type="checkbox"/> Nursing               | <input type="checkbox"/> Pain management   | <input type="checkbox"/> Home and Community Care  | <input type="checkbox"/> Mental Health      |
|  |  |   | <input type="checkbox"/> Other _____        |

15. If no, in your opinion please tell us why?

---

---

---

16. Do you provide care for people with advanced chronic diseases for people who are vulnerably housed or living homeless? ☐ Yes ☐ No

17. As a service provider, when do you think specialized care is needed for someone who is dying?

---

---

---

18. As a service provider, what do you perceive as barriers to accessing palliative and end-of-life care are for vulnerably housed and or people living homeless? Can you provide a specific example in your community?

---

---

---



19. What would assist you in supporting clients to access palliative care or end-of-life care services?

---

---

---

20. On a scale of 1-5 (1=comfortable, 5 = not comfortable) how comfortable are you discussing death and dying with clients/patients?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5

21. Can you provide us with an example of how your worldview or belief systems have served to empower or hinder the care you can or have provided a person who lives homeless or is vulnerably housed?

---

---

---

22. What recommendations would you make to improve services for people who live homeless or are vulnerably housed living with advanced chronic disease services?

---

---

---

23. What do we need to know about you as a service provider to provide the best possible opportunity to assist vulnerably housed or people living homeless to access palliative care or end-of-life care?

---

---

24. Is there something we have not asked that you would like to add at this time that could help address palliative and end-of-life care needs with those who live homeless or are vulnerably housed?

---

---

---

**Thank you for your time.**



Anishinabek Family Care

**Main Office**

200 Anemki Place  
Fort William First Nation, ON P7J 1L6

Phone: 807.623.8511  
Toll-Free: 1.855.623.8511

[www.dilico.com](http://www.dilico.com)