

# **Environmental Scan for Strengthening Residential Hospice Care in Ontario**

## **Evidence and Practice**

**Report of the Residential Hospice Working Group  
March 2015**

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# Introduction

## Purpose of Report

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The Ministry of Health and Long-Term Care (ministry), Local Health Integration Networks (LHINs), Hospice Palliative Care Ontario, Community Care Access Centres (CCACs), and other sector partners are working collaboratively to strengthen Ontario's continuum of end-of-life care and optimize residential hospices. In November 2013, a Residential Hospice Working Group was formed to provide analysis and advice to the ministry, the LHINs and the Coalition through the Provincial Palliative Steering Committee to inform the ministry's development of community-based residential hospice policy; LHIN integration and service options in the future; and sector implementation of best practice delivery for hospices aligned with Ontario's Declaration of Partnership and Commitment to Action.

This report summarizes the evidence-base that was considered by the Residential Hospice Working Group to inform its recommendations. It includes a synthesis of the evidence, practice and data gathered through an in-depth review of government and non-government publications and academic and scholarly reports that were considered relevant to the mandate of the Working Group. It delivers on the mandate of the Working Group to provide a detailed analysis of the current state of community-based residential hospices and a synthesis of evidence-based best practices to ensure that community-based residential hospices are integrated and coordinated within a continuum of palliative care services that complements without duplicating the role of home and community care, long-term care homes, and hospitals. This report was prepared as part of the Working Group commitment to building a strong and transparent evidence base to support its work.

## Part I: Policy Environment

### Context

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In December 2011, the Ministry endorsed the Declaration of Partnership and Commitment to Action (the Declaration)<sup>1</sup> as a multi-year roadmap to improve palliative care in Ontario. Through the Declaration, Ontario is developing a needs-based system that serves all citizens with life limiting illness and their families and is working with key partners to support evidence-based palliative care in clinical settings, with strong community empowerment, innovation and customization at the local level.

Through the *Declaration*, partners committed to develop best practices to optimize residential hospices to support those who cannot be cared for at home but do not require hospital care by:

- Ensuring Ontario residents have equitable access to residential hospices, where care in this setting is the most appropriate and cost-effective, based on individual and family preferences and level of need.

- Establishing an appropriate level of consistency across regions.
- Reviewing client segments (e.g., profile and needs) and care delivery models within existing freestanding residential hospices to understand any variations in delivery, cost and outcomes.
- Exploring establishing formal accountability relationships with LHINs.
- Considering innovative approaches to reduce capital costs. Examples include using existing spaces, expanded volunteer practice, etc.

Bridging the gaps between policy, practice and support requires acknowledging the challenges of medical and public health models, improving proactive integration of community-based care delivery across all sectors, enhancing the role of primary care providers, and extending research to provide an evidence-base for interventions.

## Definition

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A residential hospice is a home-like environment where adults and children with life-threatening illnesses receive end-of-life care services.<sup>2</sup>

Hospice Palliative Care of Ontario defines community residential hospices as a healthcare facility and registered charity that provides palliative care services by an interprofessional team with palliative care expertise 24 hours a day, 7 days a week in a home like setting for the individual and their significant others at no cost to the user.<sup>3</sup> Facilities incorporated in a Community Residential Hospice consist of at a minimum:

- Private residential rooms;
- Community living room, kitchen and eating area;
- Quiet area;
- Tub/Shower room;
- Public washrooms meeting accessibility regulations;
- Dirty utility area;
- Supplies area/station including secure medication room;
- Administrative offices
- Children’s play area.

## Importance of Residential Hospices

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In moving forward with implementation of their three year regional palliative plans, the LHINs have recognized residential hospices as important providers of a continuum of palliative care and have agreed to work with the ministry to develop a residential hospice policy framework and integration options through the establishment of a Residential Hospice Working Group.

The HPCO has previously put forward the following business case for residential hospice services:

An essential part of the care continuum, residential hospices are often an appropriate care setting for those who cannot be cared for in their own home, yet do not require or want to be cared for in a hospital setting. Residential hospices work in collaboration with physicians, hospitals, CCACs, and other care providers to offer a range of supportive services that are focused on the patients and their families.

Residential hospices are often used by individuals in the very last stages of their life who need more intensive care. Care in a residential hospice can provide relief for informal caregivers when a loved one is in the last stages of her or his life. In addition, evidence suggests that patients and caregivers are very satisfied with the care received in a residential hospice.

Residential hospices provide specialized and targeted care collaborated by physicians, hospitals, CCACs and other care providers, outside of a hospital setting. Unlike in most hospital settings, every member of a residential hospice has expertise and training in “palliative care, pain and symptom management and the specific needs of the dying. Care is provided with a focus on the patient and their family, allowing for individual choice in determining how to address unique needs and desires for support. This approach ensures that hospices can serve diverse communities, respecting the different practical, religious, spiritual and cultural traditions associated with end-of-life care.”<sup>4</sup>

Hospices also play a vital role in the community supporting under-served populations or targeted, including homeless patients, individuals with mental health or addiction concerns, youth patients, cancer patients and individuals with HIV-AIDS.

Within the health care continuum, residential hospices provide an alternative for care than hospitals. Coordination between hospitals and residential hospices decreases the number of ER/ALC bed days related to palliative conditions in hospitals. With adequate care provided through community supports and residential hospice beds, individuals can access the right care in the right place at the right time.

Residential hospices also receive patients directly from the community thereby avoiding hospital admission. Residential hospices provide a link between many levels of care – acute, complex, long-term and palliative. They provide an opportunity to provide seamless care across the entire health care system. The result is not only cost effective and efficient; it is also responsive to the individuals served. Residential hospices allow people to spend their last days where they choose, in a caring, home-like setting surrounded by family and friends and supported by compassionate care.”<sup>5</sup>

## Alignment with Government Direction, Strategies and Initiatives

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### End-of-Life Care Strategy

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Through Ontario's End-of-Life Care (EOL) Strategy, 34 residential hospices (RHs) or communities were announced as eligible for receiving funding from the Ministry of Health and Long-Term Care (ministry) for nursing and personal support services. \$580,000 in annual funding was allocated for nursing and personal support services based on a 10 bed model. In April 2011, the Minister committed to undertaking a provincial review of palliative care and announced a \$7M increase in base funding to RHs to strengthen nursing and personal support services. This brought nursing and personal support services funding to \$90,000 per adult RH bed and \$134,000 per paediatric bed.

### Initiatives to Support Seniors in the Community

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Dr. Samir Sinha's report, *Living Longer, Living Well*, noted that "while many Canadians would like to have access to palliative care, approximately 70% do not and where individuals do have access, it is often not equitable across diagnoses."<sup>6</sup> With respect to palliative care services in Ontario, Dr. Sinha recommended the following:

- The Ministry of Health and Long-Term Care should forge ongoing partnerships with its LHINs, the Quality Hospice Palliative Care Coalition, and other partners to implement the Vision and Action Plan identified within the Declaration of Partnership and Commitment to Action, as part of the LHINs' efforts to implement their Palliative Care/End-of-Life Three-Year Plans at the local level. (Recommendation #94)
- Ministry of Health and Long-Term Care should continue to support its LHINs in broadening the range of palliative care settings available in their regions, including within a patient's home, hospice, and institutional care settings as well. (Recommendation #95)

### Action Plan and Health Links

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The Action Plan for Health Care (Action Plan) is focused on ensuring Ontarians have:

1. Support to become healthier
2. Faster access and a stronger link to family health care
3. The right care, at the right time, in the right place

The Action Plan focus on enhancing community-based care is consistent with the actions required to improve high quality and high value palliative care:

- Faster access to primary level care in the community (family health care and house calls) that serves as the hub of our health care system
- Strengthened role of primary care in care delivery through ensuring timely access to information, education and mentorship in order to preserve specialist delivery for complex individuals

- Integration of care at a local level between primary, home and community care services
- Success is evident in more individuals receiving care in the community
- Entire health system to be held accountable for substantial progress towards fewer hospital admissions and readmissions

Ontario is improving care for seniors and others with complex conditions through Health Links. This approach encourages greater collaboration between existing local health care providers, including family care providers, specialists, hospitals, long-term care, home care and other community supports for high needs patients. With improved coordination and information sharing, palliative patients can benefit from Health Links by receiving faster care and by being supported by a team of health care providers at all levels of the health care system.

Health Links will help to ensure that patients with complex conditions:

- No longer need to answer the same question from different providers.
- Have support to ensure they are taking the right medications appropriately.
- Have a care provider they can call, eliminating unnecessary provider visits.
- Have an individualized comprehensive plan, developed with the patient and his/her care providers who will ensure the plan is being followed.

## Shared Vision, Goals and Values

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### Declaration Vision

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.

### Goals (Triple Aim)<sup>7</sup>

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#### Quality:

To improve client/family, caregiver and provider experience by delivery high quality, seamless care and support

#### Population Health:

To improve, maintain and support the quality of life and health of people with progressive life-limiting illnesses

#### Sustainability:

To improve system performance by delivering better care more cost-effectively and creating a continuously self-improving system

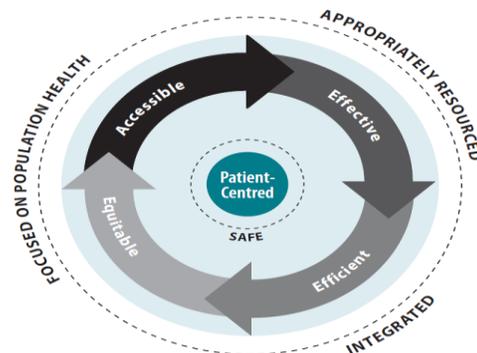
## Values

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The following values will guide the development of the report.

- 1. All Ontarians should have equitable access to high quality, value-added services to improve their experience and optimize their outcomes.**
  - Every home and community care patient and their family/informal caregivers will be able to access the appropriate level of services and support they need to ensure their total health journey is safe, equitable, appropriate, effective and efficient.
  - The system providing this care and support is population-focused, appropriately resourced, and integrated.
  - All home and community care patients with similar level of needs will receive reasonably consistent access and levels of service regardless of which geography they reside or which organization delivers their care.
- 2. The individual with a progressive life-limiting illness and their family are at the centre of care.**
  - Care is client-directed. Decisions are made by the individual themselves or their substitute decision-makers (based on an advanced care plan and prior known wishes).
  - Care is client-centred. Care providers work together to smoothly provide comprehensive care.
  - Care is also family-centred. Family members will receive care and support, both before and after a loved one's death. Family includes all relationships that are important to the individual – including relative, partner or friend.
- 3. Family members, friends and community groups provide most of the care needed.**
  - The most appropriate and sustainable system includes support for informal caregivers and volunteers. This support is vital to help them succeed in this role.
- 4. Quality is a key driver to achieve system goals.**

Nine Attributes of a High-Performing Health System



Ontario Hospital Association and  
Ontario Health Quality Council, 2009

## Part II: Population Need and Preferences

### 2.1 Key Facts

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#### Summary

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At any one time, approximately 1% of the population of a jurisdiction will be suffering from late stage chronic disease – with some variation depending on the proportion of seniors to children within the population – or about 1.3 million Ontarians.

Based on utilization data, of the patients with late stage disease, about 2/3 might be expected to die within any given year – or about 85,000 Ontarians (in addition to 9,000 sudden deaths).

Based on survey data, of the people who die, about ¾ say they would prefer to die at home (or in their long-term care home) – or about 60,000 Ontarians per year.

Of the people who died in Ontario in 2011 (Ontario Vital Statistics), about 30,000 were able to die at home.

There appears to be a gap of about 30,000 individuals in terms of aligning care delivery to population needs and preferences – this has implications for both residential hospice and community delivery options.

#### Preference Data

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Polls suggest that 70% to 80% of Canadians indicate they would prefer to die at home if supports were available but the reality is that two-thirds (67%) of Canadians died in hospital (Statistics Canada, 2007) Although 90% of Canadians indicate that they would like to die at home, 70% die in hospitals or LTC homes.<sup>8</sup>

Of the 85,000 non-sudden deaths in Ontario, less than 5 % would be expected to experience an acute complication or have need for specialized tertiary services at the end of life that could only be delivered in an acute care setting.

Estimates from the American Bar Association's Commission on Law & Aging (2003), about 4% of older adults are "unbefriended elderly" and therefore would not have the informal networks that would enable them to die at home. A similar proportion of patients with late stage disease will have support networks who are unable to cope and therefore require care in another residential setting

## Mortality

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- 90% of Canadians die from a prolonged illness (28% have a steady decline and 62% with death due to advanced chronic illness marked by slow decline) 10% have a sudden death.<sup>9</sup>
- 65% of people who died in Canada last year were not designated as dying (CHPCA)
- Seniors account for 75% of deaths each year (Carstairs, 2010) – many have non-Cancer diagnosis such as diseases of the circulatory system (35% of deaths) and of the respiratory system (about 10% of deaths) (Statistics Canada, 2005)
- Seniors make up the fastest-growing age group. In 2003, an estimated 4.6 million Canadians were 65 years of age or older, a number that is expected to double in the next 25 years.
- There will be 40% more deaths each year by 2020
- In Ontario, approximately 93,800 deaths projected for 2012/13<sup>10</sup> of which an estimated (10%) 8,900 are sudden.
- In 2009, the top ten leading causes of death in Ontario were: cancer, heart diseases, cerebrovascular diseases; chronic lower respiratory diseases; accidents; diabetes; Alzheimer's disease; influenza and pneumonia; intentional self-harm and kidney diseases.<sup>11</sup>
- 2/3 of the people who die will have two or more chronic diseases after months and years of “vulnerable frailty” (CHPCA)
- The Canadian Hospice Palliative Care Association estimates that each death in Canada affects the immediate well being of an average of five other people, or more than 1.25 million Canadians each year.

## Place of Death (Ontario)

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In 2011/12<sup>12</sup> 64% of deaths today still take place in hospitals and long-term care homes.

- Over 39,000 patients die in acute care – based on deaths in acute care hospitals (FY 2010/11) [NOTE an additional 5,000 deaths in ER, presumably without palliative care].
  - Alternatively, if you don't look at deaths but rather hospital coding of palliative, about 9,600 palliative admissions to acute care hospitals, and of these, about 7,000 deaths (Intellihealth, 2008 data)
  - Acute care hospital death rates across Ontario range from 38% in heavily populated urban areas to 70% in northern communities<sup>13</sup>
- About 6,600 residents in complex continuing care– based on deaths
- 19,000 deaths at home with or without support
- About 2,500 patients died in a residential hospice in Ontario<sup>14</sup>
  - About 19,512 active clients of visiting hospice programs – based on HPCO data
  - About 13,300 active end-of-life home care clients
    - OR about 9,000 based on deaths (FY 2010/11) – from homecare database
    - [NOTE at least ¼ of which occurred in hospitals based on older data]

- [ALSO NOTE: 67% of homecare patients NOT coded as End of Life were discharged from CCAC services because of death in 2008-2009]
- About 15,300 residents in LTCHs – based on deaths (FY 2011/12). About 1/3 of LTCH residents die each year.

NOTE – Place of Death statistics derived from Ontario Vital Statistics differ slightly from Stats Can data

## Equity Issues

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### *Equity of Access - Diagnosis*

- Adults with cancer represent a large proportion of end-of-life patients.<sup>15</sup>
- Even though cancer patients represent 28% of Canadian deaths (Statistics Canada, 2005), they make up 55% of referrals to CCACs for End of Life care (OACCAC)

### *Equity of Access - Services*

- At least 70% of Canadians who do not have access to palliative care (and when there is access, it is not equitable) (CIHI), (Carstairs, 2010)
- 16-30% of Canadians have some level of access to palliative care and support appropriate to their needs and the majority of individuals that do not have access often have a diagnosis of cancer.<sup>16</sup>
- 90% of dying Canadians could benefit from palliative care programs and services however current programs and services would only reach 20% of this segment.<sup>17</sup>
- An estimated 16-20% of Canadians in need receive palliative care and most die in institutional settings rather than dying at home as they'd prefer.<sup>18</sup>
- A total of 153,874 individuals died in Ontario between July 1, 2010 and March 31, 2012. Of the people who died, the majority (76.1%) received at least one billing for palliative care in the last 12 months prior to death. Distribution of 4 cohorts was similar across LHINs (HSPRN, 2013)
- It is estimated in one specific LHIN geography that 60% of the population will require a specialized program of Palliative Care, with many more requiring primary care Palliative Care services.<sup>19</sup>

### *Socioeconomic Status*

- UK end-of-life survey reveals socioeconomic deprivation is a major determinant of where, when and how people die. There are fewer deaths (16% of the total) in the least deprived quintile (20%) of the population. People living in the most deprived quintile are more likely to die in hospital (61%) than people living in other quintiles (54–58%). Even after taking into account the combined effects of deprivation quintile, age at death, gender and cause of death, death in hospital is more common in the most deprived quintile. Death in care or nursing homes, often the usual place of residence for the very elderly, was less common among people living in the most deprived quintile (11%) than any other quintile (16–20%). For each underlying cause (cancer, cardiovascular disease, and 'other' causes), people living in the most deprived quintile were most likely to die in hospital.<sup>20</sup>

- End-of-life costs are significant. In Ontario, the total annual cost of \$4.7B represents more than 10% of all government-funded health care (not including hospices, some physician services, and community services).
- The cost of dying in Canada has been estimated to range from \$10,000 for a sudden death to about \$40,000 for individuals with a chronic/terminal disease.<sup>21</sup> A recent study found the average health care cost to the health care system for all Ontario decedents in their last year of life was \$49,267.<sup>22</sup>
- Most deaths occur in hospital, but widespread regional variation persists. In 2007, the percentage of deaths in hospital varied by a factor of almost four across hospital referral regions, and the average number of hospice days per patient in the last six months of life varied by a factor of more than six.<sup>23</sup>
- The costs of palliative care in different hospitals can vary widely, depending on the location and approach used (Dartmouth survey). Studies comparing hospital palliative care with usual hospital care found that hospital based palliative care teams reduced hospital costs by \$7,000 per patient.<sup>24</sup>
- Some evidence suggests that, with proper design and supports, patients with late stage disease could be cared for with similar quality and costs at home, in residential hospice or hospital settings, although in practice the costs across different care settings vary widely. There is a significant cost benefit to health care systems in reducing variation and ensuring delivery systems and resources that align with patient needs and preferences
  - Early access to home care and increased homecare services reduces the risk of hospital admission by 35%.<sup>25</sup>
  - Access to palliative expert-consult teams significantly reduced the risk of being in a hospital by a third; going to the emergency room by a quarter in the last two weeks of life; and reduced the risk of dying in a hospital by half.<sup>26</sup>

## 2.2 Patient and Family Perspectives and Experiences

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### *Knowledge and Information about Palliative Care*

A survey commissioned in 2013 by Saint Elizabeth indicated that:

- 51% of Canadians would prefer to receive end of life care at home, but the majority believe it's only offered in nursing and retirement homes, hospitals and hospices. Only 11% see their homes as an option. "Professional care" is the top reason (49%) for those who would choose a hospital for end-of-life care. "More compassionate/homier" is the most popular choice (20%) for those choosing a nursing home, while "Specialized care for the dying" is the main reason (33%) cited by those choosing a hospice.<sup>27</sup>
- 70% of respondents say it is their own responsibility to make decisions related to end-of-life care, though 87% would trust family members to make decisions on their behalf.
- 10% of individuals said that it is their doctor's decision on what care is appropriate, but 57% would ask their doctor for information and advice.
- 25% of Canadians believe that end of life care is funded by provincial governments however 70% worry that they won't have enough money to pay for their own care.
- In 1997, 30% of Canadians were familiar with palliative care, compared with 60% in 2003.<sup>28</sup>

### ***Advanced Care Planning***

The March 2012 Ipsos-Reid national poll was conducted to better understand whether Canadians are engaging in advance care planning. The poll found that:

- 86% of Canadians have not heard of advance care planning.
- Less than half have had a discussion with a family member or friend about healthcare treatments if they were ill and unable to communicate.
- Only 9% had ever spoken to a healthcare provider about their wishes for care.
- Over 80% of Canadians do not have a written plan.
- Only 46% have designated a Substitute Decision Maker – someone to speak on their behalf if they could not communicate.

Research suggests that patient care planning discussions, which include the desired direction of a patient's care and advance care planning, are associated with improved quality of care and patient and family satisfaction. However, a multi-centered study completed in five Canadian tertiary care hospitals reported that fewer than one in five people had these discussions with their health care provider. Those who discussed care planning had higher overall satisfaction, and satisfaction with communication and decision-making, compared to those that did not.<sup>29</sup>

### ***Comfort Care in Hospitals***

A survey demonstrating that 70 percent of hospitalized Canadian elderly patients wanted comfort measures as opposed to life-prolonging treatment. However, more than half of these patients were admitted to intensive care units.<sup>30</sup>

### ***Place of Death Preferences***

In 2014, at the request of the Ministry of Health and Long-Term Care, Health Quality Ontario (HQO) conducted a “mega-analysis” to provide evidence to guide public policy and improve the approach to end-of-life care in Ontario. The report found certain places of death may be more appropriate or desirable for those at the end of their lives. For example, one Ontario-based study of 214 home care recipients showed that 63 percent of patients and 88 percent of caregivers preferred a home death. The analysis identifies specific factors that can help predict the feasibility of achieving a patient's preferred place of death, including: interprofessional EOL care in the place of residence; time between referral to EOL care services and death; type of underlying disease; functional status; frequency of hospitalizations during the last year of life; living arrangements, such as living with someone; presence of an informal caregiver; informal caregiver coping; patient or family preference for place of death; existence of advance directives; nursing home and hospital bed availability; availability of resources to support the patient's physical and psychological needs in the place of residence during the EOL period.

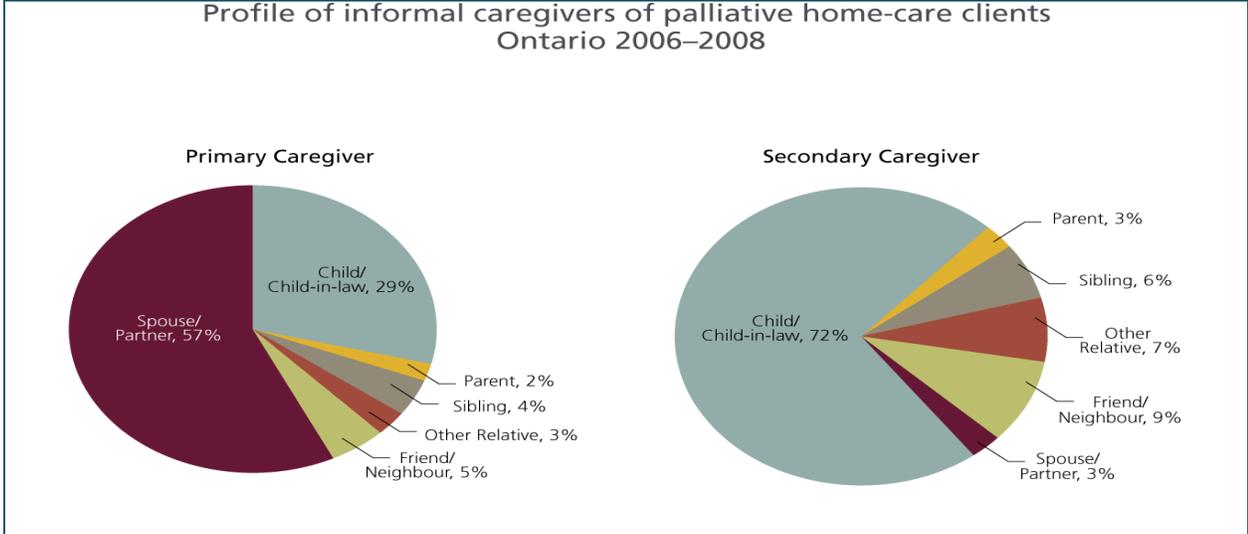
In the UK, public preferences for place of death in the nine English Government Office Regions (GORs) was obtained from a population-based telephone survey in 2010. It compares the results with a similar survey carried out in 2003 to understand how preferences are evolving over time. It goes on to contrast these preferences with actual place of death (as reported for that region) in order to shed light on how people's wishes relate to reality and to aid care planning so that preferences are more frequently met. The majority of participants in all regions said that they would prefer to die at home if circumstances allowed, ranging from 60% in West Midlands to 67% in the North East. Hospice was the

second most frequent choice, especially in the South East and the East of England (where about a third of participants chose this). Home and hospices together accounted for the preferences of at least 89% of participants in every region. As age increased, a preference to die at home decreased while a preference to die in a hospice increased (except for the group aged 55-64). Preferences for home death ranged from 45% (for those aged 75+) to 75% (for those aged 25-34). The majority of deaths in 2010 took place in hospitals (53%) and only 21% died at home. Across the country, there is a major gap between the proportion who prefer to die at home and the proportion of actual home deaths – this gap is smaller in the West Midlands (39%) and larger in the North East (46%), but remains wide whichever area is reviewed.<sup>31</sup>

**Supporting Informal Caregivers**

Canadian studies report that friends and family provide most of the care (80%) for people who are frail, elderly, and/or have disabilities.<sup>32 33</sup> This contribution saves Canada’s health-care system \$31 billion a year.<sup>34</sup>

There is often more than one person caring for a dying friend or family member. In 2006–2008, more than half (57%) of palliative care clients in Ontario were cared for primarily by their spouses or partners, while a third (29%) received most of their primary informal caregiving from their children or children-in-law. Secondary caregivers were more likely to be children or children-in-law (Figure 1).

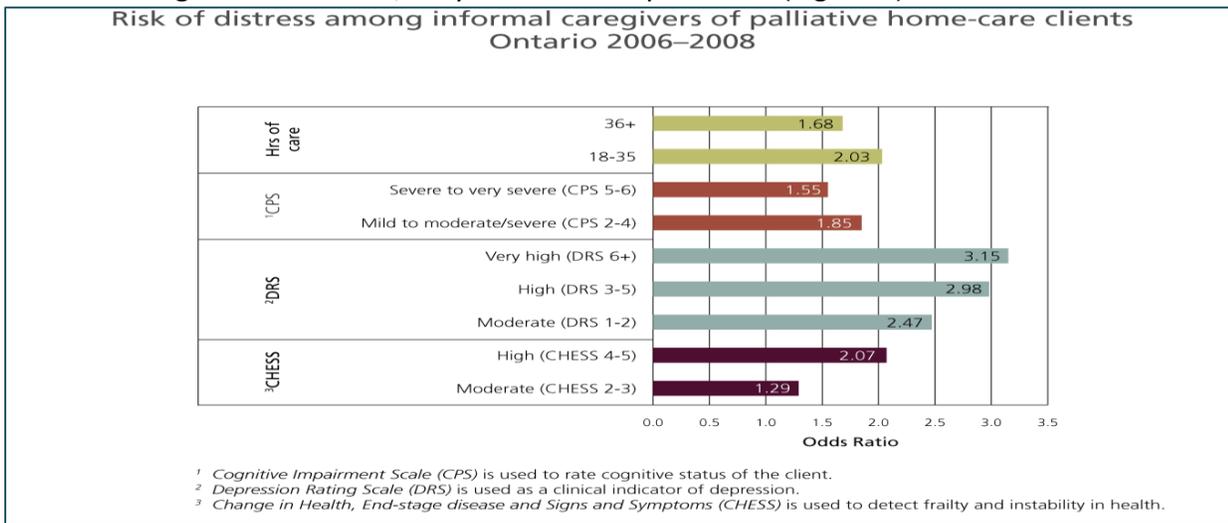


**Figure 1: Profile of Informal Caregivers of Palliative Home-Care Clients Ontario<sup>35</sup>**

Most caregivers found caring for loved ones manageable and rewarding. However, more than one in four (22%) showed signs of distress, including anger, depression, being overwhelmed and unable to continue providing care. Caregivers of 12% of Ontario palliative home-care clients exhibited more than one sign of distress.

Longer hours of informal care and the health status of palliative home-care clients led to significant caregiver distress. Those who provided 18–35 hours of care had high levels of distress. Interestingly, as care topped 36 hours, caregivers learned to manage better. The dying person’s health status—health decline, depressive symptoms and cognitive impairment—also added to caregiver distress. As the health of the loved ones deteriorated and/or depressive symptoms escalated, caregiver distress

increased. A mild/moderate decline in cognition of palliative home-care clients was stressful for informal caregivers. Over time, they learned to cope better. (Figure 2)



**Figure 2: Risk of Distress among Information Caregivers of Palliative Home-Care Clients Ontario 2006-2008**

### **Aboriginal Communities and Peoples**

The largest numbers of people with Aboriginal ancestry in Canada live in Ontario on 207 reserves and settlements. There is a need to facilitate better quality of living and dying in many ways, including through enhancing access to palliative care in these communities. International qualitative studies document the common aboriginal preference to die at home<sup>36</sup>. Limitations in community resources inhibit this option in remote areas.

Terminally ill patients and their family members face difficult decisions. When health care workers are not of the same cultural background as the patient, communication and decision making take on new challenges. Some of the challenges and barriers that arise when dealing with end-of-life care for aboriginal patients and their families are the creative tension between individual care decisions and family and community values, traditional and holistic concepts of health and dying, respectful communication and geographic isolation and its effects on medical resources<sup>37</sup>.

The lack of culturally relevant information and services focused on end of life care for Aboriginal individuals and families make it difficult for health care providers and their Aboriginal patients to have meaningful dialogue on palliative care and to make care plans that consider and respect cultural values and beliefs. For example, a recent report (April 2014) from Waterloo Wellington LHIN regarding aboriginal palliative care found that with the growing urban Aboriginal population, culturally respectful and appropriate palliative care and end of life care models must be developed for urban centres.

### **Multicultural Communities**

Ontario has a large multicultural population, mostly concentrated in large urban areas. It is estimated that 6.5% of all immigrants (and 15.6% of immigrants who are 65 years and older) in Ontario are unable to conduct a conversation in English or French.<sup>38</sup>

Culture and religion may shape the clients values, norms and perspectives regarding palliative care. This can include the client's and family's perspective on health, suffering, death and dying, preferences for a home, hospice or hospital death, the use of Western medicine, the role of informal/family caregiving, the provision of information about the likely outcome of the illness, and the role of the patient and family in the decision making process. These clients are also likely to experience challenges when attempting to navigate the system and access support. This is exacerbated by the fact the some healthcare providers may lack the skills required to effectively engage with clients of different cultures, social-economic backgrounds and languages.

Evidence indicates that there is a need for specific training and education for healthcare providers in the palliative approach given that front-line staff often think that they lack the knowledge and skills to provide quality care to end of life patients. Some healthcare providers may lack the skills to communicate about sensitive end-of-life issues with their patients and to involve patients in decisions about the various treatment options. Some providers may also not understand how clients make decisions. All these factors suggest that culturally-sensitive palliative care is required to meet the needs and expectations of a growing immigrant population in the province.

### ***Satisfaction with Hospice Services - United States***

A study was conducted to identify which processes of care were associated with greater satisfaction with hospice services from the perception of bereaved family members. A total of 116,974 surveys from 819 hospices in the United States were obtained via the 2005 Family Evaluation of Hospice Care, an online repository of surveys of bereaved family members' perceptions of the quality of hospice care maintained by the National Hospice and Palliative Care Organization. Bereaved family members were more likely to rate overall satisfaction with hospice services as "excellent" if they were regularly informed about their loved ones, they felt the hospice team provided the right amount of emotional support to them, they felt that the hospice team provided them with accurate information about the patient's medical treatment, and they could identify one nurse as being in charge of their loved one's care. These four key processes of care appear to significantly influence an "excellent" rating of overall satisfaction with hospice care.<sup>39</sup>

### ***Quality of Care – United States***

This report highlights the key findings from the first national VOICES (views of informal carers for the evaluation of services) survey of bereaved people, which was undertaken by the Office for National Statistics (ONS) on behalf of the Department of Health. The overall aims of the survey were to assess the quality of care delivered to people in the last three months of their lives in the United States and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients. Around one half (51%) died in hospital, with 21% dying at home, 22% in home care and 6% in a hospice. Overall, 12% rated the care given as outstanding, 30% as excellent, 33% reported care as good, 14% as fair and 10% as poor. The highest proportions of ratings as outstanding were for patients who died in hospices (20%) and at home (19%) compared with 7% for hospitals. The survey also reveals some substantial variations in quality of care and support for carers by Primary Care Trust cluster, showing areas where further improvement is needed.<sup>40</sup>

### ***Evaluating and Improving the Quality of Palliative Care in All Settings - National VOICES survey (United Kingdom)***

As part of the End of Life Care Strategy, the Office of National Statistics has implemented the a national VOICES survey (views of informal carers for the evaluation of services) (NHS Department of Health, 2012b), which was designed to establish a systematic record of the quality of care experienced by people in their final three months of life. The findings provide benchmarks for outcomes across key questions relating to topics such as perceptions of quality of care, dignity and respect show by doctors and nurses, and death in place of preference. According to this survey:

- Approximately half of patients (51%) died in hospital, with 21% dying at home, 22% in home care and 6% in a hospice.
  - Overall, 12% rated the care given as outstanding, 30% as excellent, 33% reported care as good, 14% as fair and 10% as poor;
  - The highest proportions of outstanding ratings were for patients who died in hospices (20%) and at home (19%) compared with 7% for in hospitals (NHS Department of Health, 2012b).b

### ***Family Evaluation of Hospice Care Survey (United States)***

The National Hospice and Palliative Care Organization (NHPCO) in the US compiles and maintains results from online surveys of bereaved family members of patients who had received hospice care at end of life. Respondents are contacted one to three months after their loved ones have died. The survey provides an evaluation tool that enables hospice agencies to evaluate and improve service delivery (Rhodes et al., 2008).

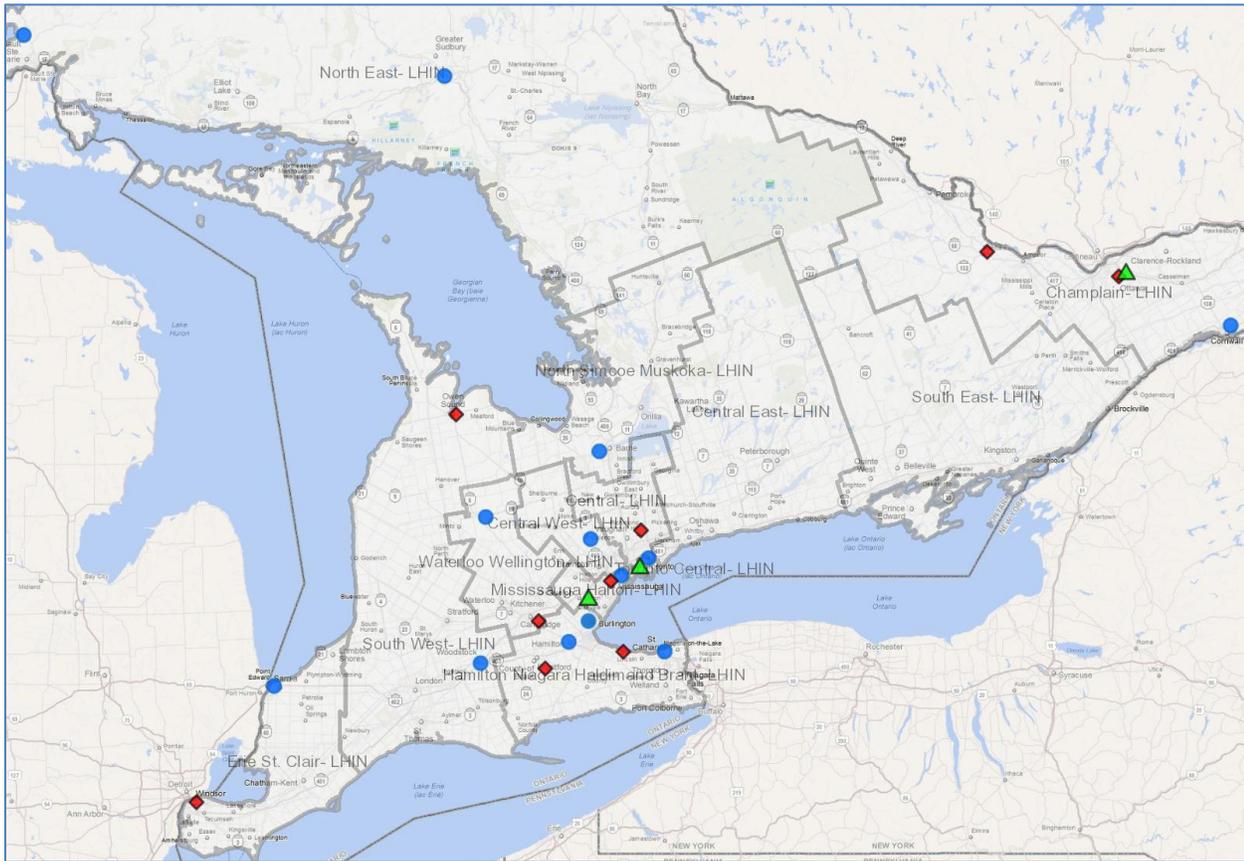
According to an article that analyzed results from the 2005 survey, bereaved family members were more likely to have achieved higher satisfaction with hospice services if certain key processes of care were achieved. These processes included regular and accurate communication about the patient's medical condition by the hospice team, provision of adequate amounts of emotional support by hospice staff, and the family's belief that hospice staff was knowledgeable enough about a patient's medical history to provide the best possible care (Rhodes, et al., 2008).

# Part III: Current Palliative Delivery Landscape

## 3.1 Residential Hospices in Ontario

There are currently 34 ministry approved residential hospices however to date only 26 hospices with 212 beds are operational.<sup>41</sup> Of the 26 ministry funded residential hospices in Ontario, 23 are adult and 3 are pediatric hospices.

**Geographic Distribution of Ministry Funding Residential Hospices (October 2013)**



### Legend

- Residential hospices with 10 beds
- ◆ Residential hospices with less than 10 beds
- ▲ Pediatric residential hospices

**Table 1: MOHLTC Residential Hospice Beds Per 100,000 By LHIN**

<b>LHIN</b>	<b>Number of Hospices</b>	<b>Ministry Funded Beds</b>	<b>Beds Per 100,000 People*</b>
<b>Central</b>	1	3	0.17
<b>Central East</b>	0	0	-
<b>Central West</b>	1	10	1.21
<b>Champlain</b>	4	33	2.69
<b>Erie St. Clair</b>	2	18	2.80
<b>Hamilton Niagara Haldimand Brant</b>	5	42	2.99
<b>Mississauga Halton</b>	3	18	1.55
<b>North East</b>	2	20	3.53
<b>North Simcoe Muskoka</b>	1	10	2.19
<b>North West</b>	0	0	-
<b>South East</b>	0	0	-
<b>South West</b>	3	26	2.26
<b>Toronto Central</b>	2	16	1.40
<b>Waterloo Wellington</b>	2	16	2.14
<b>Total</b>	26	212	1.54

Table 1: MOHLTC funded residential hospices beds per 100,000 of the population by LHIN.

\*Registered Persons Database (2010)

In addition, see page 52 in the RHWG report for a more detailed summary of both current and planned residential hospice beds, including ministry approved hospice beds (212 current and 90 planned), LHIN funded but not ministry approved hospice beds (49 current and 32 planned) and community funded beds (11 current and 87 planned).

A detailed description and analysis from the sector is provided in the appendix in this report.

## **Funding**

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The annual cost of a 10-bed residential hospice: \$1,600,000.

Ministry funding for residential hospices in 2013/14 was \$19,266,218. Adult residential hospices receive \$90,000 per bed and pediatric hospices receive \$134,000 per bed. The funding is provided by the LHIN to the CCAC. The estimate CCAC cost for service to adult RHs is \$2,086 per patient or \$116 per patient day.

The ministry offers funding for nursing and personal support services in approved residential hospices, as well as access to other services provided through the CCACs based on client need (such as case management, other professional services, drug benefits, medical supplies and equipment).

Funding is for costs related to nursing and personal support services only and does not cover other operating costs.

Annual fundraising required by local community to operate 10 beds is \$680,000.

- Other operating costs include administration, meals, maintenance and capital expenses.<sup>42</sup> Typical capital cost fundraised 100% by the local community to build a 10 bed hospice can range from \$3,000,000 to \$5,000,000.
- Hospice palliative care programs are at least 50% funded by charitable donations.<sup>43</sup> (HPCO)

Residential hospices can either:

- Receive a funding envelope to independently employ nursing and personal support services, with an accountability agreement through the CCAC; or
- Receive nursing and PSS through CCAC-contracted service providers.<sup>44</sup>

RHs are permitted to retain 100% of the funding provided the hospice maintains a minimum of 80% occupancy. If occupancy is less than 80%, the amount of subsidy the RH is permitted to retain is reconciled based on actual bed resident days.<sup>45</sup> The only exception to the annualized funding for the RH would be if the client needed the services of a specialized nurse.

### Residential Hospice Patient Profile and Utilization

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- Patients with life-limiting illness.
- Over 20% of patients admitted to RH have a cancer diagnosis. Almost 24% are aged 65+. Nearly all patients admitted to hospice die there<sup>46</sup>
- Over half of patients admitted to residential hospices come directly from their homes.
- In 2012-13, the average length of stay was 19 days
- In 2012-13, over 2500 patients died in a residential hospice in Ontario. There are approximately 86,000 deaths in the province each year.<sup>47</sup>
- Of the 6200 referrals made to RHs in 2012-13, about 45% of patients are admitted.<sup>48</sup>
- In 2011, 19% of referrals died while waiting for admission.<sup>49</sup>

### Legislative and Regulatory Framework

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Residential hospices are not health service providers under the *Local Health System Integration Act, 2006*.

The provision of nursing, personal support and other community services to residents in residential hospices must comply with the requirements of the *Home Care and Community Services Act, 1994* (HCCSA).

The CCAC Case Manager is responsible for determining client eligibility for nursing, PSS and all other services provided through the CCAC. Eligibility for services includes:

1. Valid Ontario Health Card

2. Living with a life limiting or life threatening health condition and has a limited life expectancy, regardless of the diagnosis;
3. The client must require nursing and PSS; and
4. The client must require these services in the RH setting.

A patient would receive access to a RH after being determined eligible by the CCAC following an assessment by a case manager. CCACs manage waitlists for persons who cannot be immediately admitted to a RH, however, there may be local variation in practices. Where patients are on waitlists, the CCAC may arrange for in-home services to be provided.

The residential hospice is responsible for reviewing all applications for admission from the CCAC and determining the hospice's ability to safely meet the care needs of the potential client before admitting them to the hospice.<sup>50</sup> Admission requirements for one RH is restricted to cancer patients.

### Accountability Framework

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The CCAC will negotiate an accountability agreement with the RH using the template developed by the OACCAC. Considerations include:

- The RH is operating in compliance with the HAO RH Standards
- The CCAC Case Manager is responsible for determining client eligibility for nursing, person support and all other CCAC services, prior to/ a client being admitted to the hospice
- Funding can only be used for nursing and personal support services for clients in RH beds (funding cannot be used for administrative functions).
- A RH provides on-site coverage 27/7<sup>51</sup>

If the residential hospice chooses to have all services provided through the CCAC, including nursing and personal support, then the service provider is the agency that has the contract with the CCAC. This option does not require an accountability agreement between the CCAC and residential hospice.<sup>52</sup>

### Admission and Assessment

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Hospices admit based on the availability of the bed, the readiness of the client to relocate to hospice on short notice and the availability of CCAC staff to conduct an assessment after hours and on weekends. In some locations, the hospices work with the local hospital to identify patients for transfer to hospice and to assist with the applications. Some hospices also have arrangements with their CCAC to permit the hospice to admit after hours providing that the client meet the CCAC criteria and that the CCAC validates the assessment after the fact.

### Wait List Considerations

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Hospices triage referrals and admit based on prognosis, acuity and need, all of which may change between the time a client requests placement on the wait list and when the hospice is ready to admit. For example, hospices are often asked to put someone on a wait list in anticipation of future need.

When adequate home care is provided, some of these clients will die at home without needing a hospice admission. Should a client on a wait list request admission, they are reassessed and admission will depend on their immediate prognosis, acuity and need regardless of how long they have been on the wait list.

## Staffing and Health Human Resource Considerations

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For RHs that choose to be the employer, staffing standards include:

- 24/7 RN coverage (based on HAO Residential Hospice Standards)
- Appropriate mix of nursing (RN and RPN) and PSS staff based on the number of beds
- Minimum of two staff on site 24/7

In order to ensure the highest quality care and service to meet the often complex medical, spiritual and emotional needs of our residents and their families, residential hospices are required to recruit staff with highly developed and unique competencies and specializations in hospice palliative care.

Residential hospices are committed to creating a sustainable future for health care through the utilization of New Grad Programs, such as through RNAO, and preceptor programs in order to employ a staffing mix that builds capacity in the system at the same time as finding efficiencies. The experience of the residential hospices has shown that dedicated clinical leadership is required to ensure quality care and patient/staff safety.

Human resource requirements have grown as a result of the quality standards for services provided. The original staffing model was also dependant on volunteers in key non-nursing roles that are now required by the Ministry of Labour to be filled by paid staff, whose function can be supported by volunteers. Examples include food service/kitchen coordination and housekeeping supervision. The need for ongoing training and development for staff in all areas of operation has also increased.

With the growth in residential hospice programs across the province, has come greater emphasis on the development of practices, policies, standards and human resource skills in the areas of infection control, health and safety standards and other areas of risk management . These include but are not limited to: storage and management of medications including narcotics; handling and disposal of hazardous or contaminated waste; food preparation and handling and maintenance of a home-like setting while adhering to infection and disease prevention standards. The overall goal in the provision of residential hospice service continues to be the provision of high quality care within a compassionate caring environment.

## Other Care Standards

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Residential hospice sector partners developed standards in 2005 entitled “Community Residential Hospice Standards” which set out the expectations for community residential hospices in Ontario. Residential hospice beds are not licenced.

Buildings must meet the *HAO Community Residential Hospice Standards* and the site must be ready to serve clients in order to receive funding.<sup>53</sup>

### 3.2 Other Care Settings

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Palliative care is delivered in a variety of care settings in Ontario, including in-home, long-term care homes, by community support services agencies, and through integrated community-based teams:

Palliative Settings	Patient Profile
<b>Residential Hospice</b>	Clients with life threatening progressive or terminal illness nearing the end of the illness trajectory, who require care to sustain comfort and quality of life.
<b>In-Home and Community Care</b>	Clients who receive care in-home and through community supports generally have informal caregivers to support their care beyond their assessed service provision
<b>Acute Care</b>	Clients whose condition progresses and requires intensive care beyond that which is provided in a residential hospice may end up in an acute care setting. In addition, patients at the end-of-life who are still receiving curative treatments may be better served in a hospital setting.
<b>LTC Homes</b>	Long-term care homes also provide palliative services to those at the end-of-life, but generally for older patients
<b>Primary Care</b>	Provision of care through home visits to clients who receive care in-home with informal caregiver support.
<b>Complex Continuing Care</b>	Complex continuing care (CCC) is a designation for hospital beds or facilities where specialized services for medically complex patients with chronic illnesses or disabilities are provided, sometimes over extended periods of time.

### Community Services

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#### Community Support Services

- Caregiver Support Service, Volunteer Hospice Visiting Service: volunteers are specially trained and recruited to provide support to those who are receiving palliative care. Bereavement support is also a part of this service.
- Pain and Symptom Management: This service provides funding for a pain and symptom management team to support primary care providers in the community.
- Palliative care education and consultation services.

- Physician Palliative Care Education and Community and Long-Term Care Facility Palliative Care Interdisciplinary Education: This funding supports physicians’ education as well as education for front line health care staff in the community and long-term care homes.

### Primary Care

- Canada has approximately 200 palliative care physicians who work full-time or part-time.<sup>54</sup>
- Physician Community Palliative Care On-Call Program (future): The Health Services Branch of MOHLTC is working on a community palliative care on-call program as part of commitments made in the 2008 Physicians Services Agreement (PSA). They have been working with the OMA under a sub-committee of the Physicians Services Committee (PSC) to develop eligibility criteria, framework, and funding for the program.

### In-Home Care

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CCACs play a key referral role for palliative care services. Case managers may assess palliative client needs, determine eligibility for services, develop a plan of service and arrange for home care services and placement in other care settings, such as a long-term care home or refer to a residential hospice setting. CCACs can also provide information on how to access community support services. CCAC in-home personal support services are not subject to service maximums at the end-of-life.

In-home CCAC services are legislated by the *Home Care and Community Services Act, 1994*. Care generally involves regulated professions (such as nursing, rehab services, social work, dietetic and pharmacy services) but also includes personal support and homemaking services. CCACs are accountable for funding and services with the LHINs through the Service Accountability Agreement (SAA). Ministry and LHIN accountability requirements are identified through the Ministry-LHIN Performance Agreement (MLPA)

CCACs also buy medical supplies, laboratory and diagnostic services, rent hospital and sick room equipment, arrange transportation to other health services and authorize access to drug cards for people who receive in-home professional services.

In September 2011, the minister approved funding of \$8.169 million annually for 70 CCAC Nurse Practitioners in palliative care (5 per LHIN). The 70 Palliative Care Nurse Practitioners will support clients with complex needs, those at high risk and those with chronic needs

In 2012/13,<sup>55</sup>

- The average cost per palliative client was \$5,428.98.
- CCACs helped 25,000 individuals through their death experience.
  - Projected death estimates in Ontario were 93,390.<sup>56</sup>
- The average palliative client received over 11.45 hours of nursing care and 77.55 hours of personal support service.

Based on a survey conducted in 2012 to 2013, caregivers in Ontario are generally satisfied with aspects of palliative home care. Other findings from the survey indicated<sup>57</sup>:

- 70% indicated that they received as much help and support from health and supportive services as they needed when caring for their loved one.
- 20% indicated that pain was relieved all of the time during the last three months of the patient's life while 32% indicated that pain was relieved completely only some of the time. 3.9% (or 8 respondents) indicated that pain was not relieved at all.
- 91% of caregivers indicated they knew how to contact home care providers any time assistance was needed with an urgent problem.
- 54% of caregivers indicated they had to contact a health professional for an urgent matter in the evening and/or weekends during the last three months of their loved one's life.
  - 44% of caregivers indicated they contacted homecare while 27% contacted the family doctor/after-hours physician. 17% contacted 911.
- In response to after-hours urgent matters, 30% of patients were visited by homecare, 22% were visited by a palliative care doctor or another doctor (other than the family doctor). 0.7% were visited by a hospice volunteer at home. 26% were advised to go to an emergency department or call 911.
- 45% of caregivers indicated their overall impression of care during the last three months of life was excellent. 26% indicated it was outstanding, 1.5% indicated it was poor.

## Care in Acute Care Settings

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In 2013/14, there were 37,397 'palliative deaths' in hospital, i.e. deaths of hospital patients for reasons other than a significant trauma or injury. This figure represents 3.8% of all hospital discharges. This was a very slight decrease from 2012/13, when there were 37,869 palliative patients (3.9% of total hospital discharges).

Between April 2010 and December 2012, nearly half of all palliative deaths in Ontario occurred in an acute care setting. However, over that period, the percentage of palliative deaths in an acute setting did decline by approximately 7.5%, and the percentage of palliative deaths at home increased by 19.5%.

### Alternate Levels of Care (ALC)

Approximately 1/3 of ALC patients at any given time require palliative care (Drummond 2011). Recent analysis suggests that the total number of ALC patients requiring palliative care declined slightly between 2008/09 and 2013/14.

Data from the Wait Times Information System maintained by Cancer Care Ontario shows that in FY 13/14, ALC days for patients discharged from acute, rehab, or CCC beds to palliative care represented 3% of ALC days for all patients discharged from those settings.

## **Small and Rural Hospitals**

2,288 deaths occurred in small rural hospitals, accounting for 6.1% of all deaths in acute care hospitals and 2.7% of total deaths across Ontario. (IntelliHealth, MOHLTC, 2014).

The mean proportion of palliative deaths as a percentage of total discharges has slightly increased for small rural hospitals and slightly decreased for non-small, rural hospitals.

## **Complex Continuing Care**

Complex continuing care (CCC) is a designation for hospital beds or facilities where specialized services for medically complex patients with chronic illnesses or disabilities are provided, sometimes over extended periods of time. CCC patients need care that is on-site and at a level of intensity that exceeds the care available at home or in long-term care homes. Specifically, CCC patients require hospital admission and the availability of 24 hour nursing and physicians, regular onsite medical management, highly-skilled and often technology-based care, frequent re-assessments, and active care management by specialized staff.

The types of services provided in CCC facilities include rehabilitation of medically complex patients, slow-paced rehabilitation for those with lower tolerance for intensive rehabilitation and who need a longer duration of care than can be provided in inpatient rehabilitations programs, respite care, and palliative care.

Palliative Care Units (PCUs) in CCC hospitals are focused on providing end-of-life care and support to patients who have a prognosis of less than 3 months to live and when the patient and their family are having difficulty managing at home.

A number of assessment tools are used by health care professional to inform decision-making about the appropriateness of inpatient palliative care. For example, the Palliative Performance Scale is used to assess how well patients are managing with their ability to ambulate, level of activity and evidence of disease, self-care abilities, food and fluids intake, and level of consciousness.

In 2009/10, 34% of CCC patients died in hospital (Source: CCRS Quick Stats Tables for CCC facilities in Ontario).

In 2013, 12.5% of all CCC patient discharges (3,221 out of 5,742) died within 14 days of admission to the CCC bed. The number of patients dying within 14 days of admission to a CCC bed has increased by 32.4% between 2008 and 2013, from 2,432 to 3,221. (source: IntelliHealth, MOHLTC, 2014)

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## Care in Long-Term Care Homes

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In accordance with section 42 of Regulation 79 of the *Long-Term Care Homes Act*, all LTC homes shall ensure that every resident receives end-of-life care when required in a manner that meets their needs.

## Integrated Palliative Care Teams/Programs

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A variety of programs are currently underway in LHINs across the province that aim to improve the integration of care teams, education for providers, and provide more seamless transitions of care.

A study of the effectiveness of expert-consult teams in Ontario was conducted in 2013 to determine why some teams were able to reduce late-life acute care use whereas others were not able to. The analysis demonstrated that expert-consult teams, relative to standard usual care (defined as care delivered by the home care system) significantly reduced the risk of being in a hospital by a third or going to the emergency room by a quarter in the last two weeks of life. Furthermore, exposure to the intervention reduced the risk of dying in a hospital by half. The effectiveness of the team is contributed to the capacity to anticipate clinical problems and making care arrangements in advance. Teams would monitor client symptoms and constantly monitor the patient's condition and quickly respond to changes in condition.<sup>58</sup>

## Voluntary Care Sector

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In 2010/2011 Hospice volunteers gave more than 700,000 hour of care to over 21,000 individuals receiving hospice palliative care at home.

Hospice volunteers provide emotional and physical care to the dying and emotional support and respite to family caregivers. Hospice volunteers also provide bereavement support to both patients and families before death and to families after the death of their loved one.

## Part IV: Detailed Resource and Reference Material

### 4.1 An Overview of Residential Hospices (HPCO)

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#### What is a Residential Hospice?

A Community Residential Hospice is a healthcare facility and registered charity that provides palliative care services by an inter-professional team with palliative care expertise 24 hours a day, 7 days a week in a home like setting for the individual and their significant others at no cost to the user. Community Residential Hospices have in-patient resident beds up to a maximum of 10 beds. There are minimum Regulated Health Care Professional staffing requirements for all Community Residential Hospices.

Community Residential Hospices are funded in part by the Ministry of Health and Long Term Care and in part from charitable donations and fundraising. All Community Residential Hospices must comply with relevant provincial and federal legislation and regulations that govern registered charities and healthcare facilities.

Community Residential Hospices are integrated partners with other healthcare organizations such as Community Care Access Centers, local hospitals, and visiting hospice volunteer programs.

Care in a residential hospice facility is offered at no cost to the patient or family.

Facilities incorporated in a Community Residential Hospice consist of at a minimum:

- Private residential rooms
- Community living room
- Community kitchen and eating area
- Quiet area
- Tub/Shower room
- Public washrooms meeting accessibility regulations;
- Dirty utility area
- Supplies area
- Nursing station including secure medication room
- Administrative offices
- Children's play area

Residential hospice care is essential for people living with the challenges of a life-threatening illness and who can no longer be cared for in their own home, yet do not require the care of an acute care hospital. Residential hospices work in collaboration with physicians, hospitals, the CCACs and other care providers to facilitate integrated and seamless access to a variety of care needs. They offer a range of supportive services for patients and their families that are best provided outside a hospital setting. A palliative treatment approach provides supportive, comfort-based care as opposed to aggressive, curative treatment. Care is provided with a focus on the patient and their family, allowing for individual choice in determining how to address unique needs and desires for support. This approach ensures that hospices can serve diverse communities, respecting the different practical, religious, spiritual and cultural traditions associated with end-of-life care.

## **The Residential Hospice Standards and Model of Care**

Each Community Residential Hospice has a model of care, which is collaborative in nature and provides palliative care using a holistic approach through an interprofessional team that has expertise in palliative care.

The model of care is based on the 2005 Canadian Hospice Palliative Care Association's *A Model to Guide Care; Based on National Principles and Norms of Practice*.

Hospice Palliative Care Ontario published the first standard for residential hospices in Canada in 2005. The standard was updated in 2011. The standards address clinical care; governance; operations; and quality assurance with 15 defined standards which are:

### **Section A – CLINICAL CARE**

- Standard A1. Model of Care
- Standard A2. Access to Hospice
- Standard A3. Assessment
- Standard A4. Information Sharing
- Standard A5. Care Planning
- Standard A6. Care Delivery

### **Section B – GOVERNANCE**

- Standard B1. Board of Directors
- Standard B2. Financial
- Standard B3. Fundraising

### **Section C – OPERATIONS**

- Standard C1. Facility Design and Risk Management
- Standard C2. Human Resources
- Standard C3. Volunteer Involvement

### **Section D – QUALITY ASSURANCE**

- Standard D1. Operations
- Standard D2. Individual and Provincial Sustainability
- Standard D3. Research and Education

The HPCO Community Residential Hospice Standard requires that:

- The Community Residential Hospice will address the psychosocial, physical, practical and spiritual needs of the resident, be adult or child, and their significant others with the aim to improve quality of life
- The Community Residential Hospice will develop a treatment plan based on the assessment of those needs
- The Community Residential Hospice will implement the plan using interprofessional teams of professionals with expertise in hospice palliative care aiming to deliver symptom control and improve quality of life
- The Community Residential Hospice will utilize the assistance of volunteers according to each individual hospice's needs

The Standard also requires that the Interprofessional Team includes:

Professional Staff:

- Regulated Healthcare Professionals: Registered Nurses, Registered Practical Nurses, Nurse Practitioners, Physicians, Pharmacists, Physiotherapists, Social Workers, Social Services Workers.

- Non-regulated Healthcare Professionals: Personal Support Workers, Paramedics, Music Therapists, Spiritual Care Therapists, medical students, nursing students, other healthcare students

Other members of the team:

- Significant others of the person: Family, friends if they choose to be involved
- Resident: The person receiving care
- Volunteers: members of the public who have undergone specific training, of at least 30 hours, in hospice palliative care

The minimum nursing requirement in the HPCO standard is defined in Standards A6.1 *“The Community Residential Hospice has a Registered Nurse on site 24 hours a day 7 days a week.”* **History & Development**

The first residential hospice in Ontario opened with six beds in Oakville in 1997. By 2002, there were seven locations operating 45 beds without any government funding. In October 2005, MOHLTC announced \$27.1 million in funding for the existing seven plus an additional 27 locations to be built over several years. Including the original seven, a total of 34 locations and 296 beds were approved for funding.

Of the 34 announced locations, 26 are operational (212 beds) and eight are in planning/development. In addition to the MOHLTC funded beds LHINs are funding seven residential hospices (49 beds) using other LHIN dollars and four residential hospices (11 beds) operate without any government funding. A total of 37 locations and 272 beds are now open.

There are 21 residential hospices in planning/development: Eight (80 beds) sites have MOHLTC approved funding; four sites (32 beds) have LHIN approved funding (two (12 beds) of these sites are currently under construction); and nine sites (66) have no government funding approved. Four existing sites are planning to expand by a total of 18 additional beds but have not received funding approval.

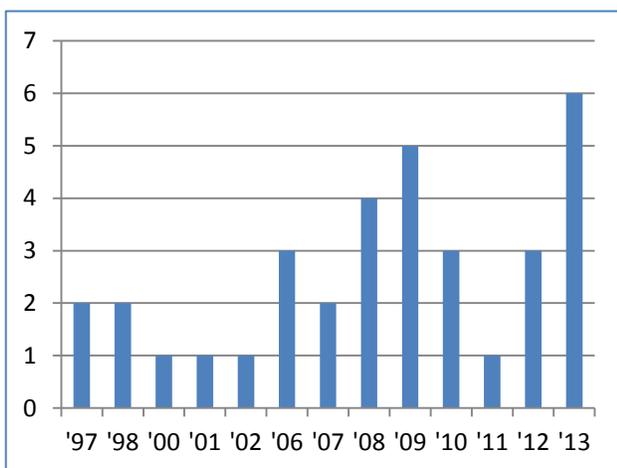


Chart 1 Hospice Openings by Year

Ian Anderson House in Oakville opened in 1997 and was the first residential hospice to open in Ontario. Although Casey House opened in 1988, it is classified and funded as a small hospital.

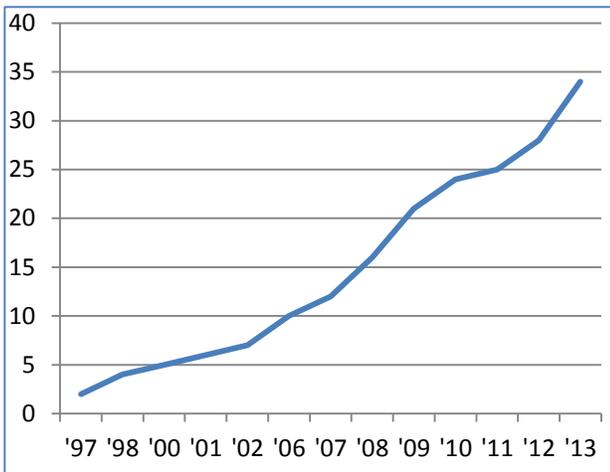


Chart 2 Hospice Growth (locations) by

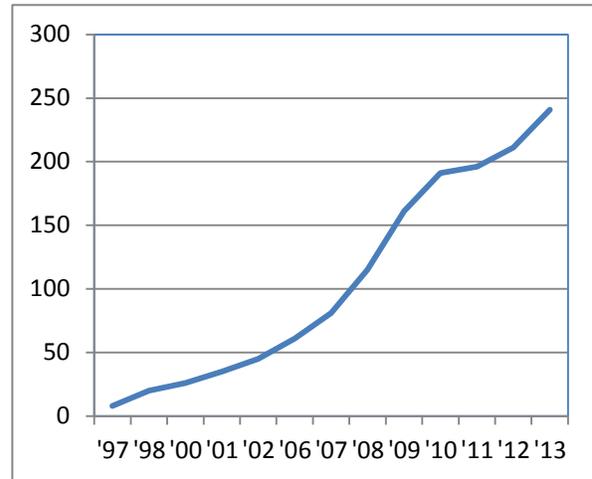


Chart 3 Hospice Growth (beds) by Year

### Residential Hospice Summary of Locations and Beds

In all of the tables in this section, the **MOH Funded** column refers to the sites approved for funding in the 2005 announcement; the **LHIN Funded** column refers to sites funded by the LHIN from dollars other than the 2005 announcement.

Bed Summary	Source of Funding			Total
	MOH RH Funded <sup>1</sup>	LHIN Funded <sup>2</sup>	Unfund ed	
Open Sites	26	7	4	37
Open Beds	212	49 <sup>3</sup>	11	272
Sites under construction	0	2	0	2
Beds under construction	0	12	0	12
Planned Sites	8	2	9	19
Planned Beds	80	20	84 <sup>4</sup>	184
<b>Total number of sites (open/const./planned)<sup>3</sup></b>	<b>34</b>	<b>11</b>	<b>13</b>	<b>58</b>
<b>Total number of beds (open/const./planned)</b>	<b>292</b>	<b>81</b>	<b>95</b>	<b>468</b>

Table 1 Residential Hospice Site and Bed Summary

<sup>1</sup> MOH RH means funding from the 2005 MOHLTC announcement of 34 residential hospices

<sup>2</sup> LHIN Funded means LHIN funding other than from the 2005 MOHLTC residential hospice announcement

<sup>3</sup> Seven sites with 49 beds

<sup>4</sup> 9 new sites with a total of 66 beds and 4 existing sites adding a total of 18 beds

### Open Residential Hospice Site by LHIN

LHIN	MOH RH Funded <sup>1</sup>		LHIN Funded <sup>2</sup>		Unfunded		Total	
	Sites	Beds	Sites	Beds	Sites	Beds	Sites	Beds
1. Erie St. Clair	2	18					2	18
2. South West	3	26					3	26
3. Waterloo Wellington	2	16					2	16
4. Hamilton Niagara Haldimand Brant	5	42	1	10			6	52
5. Central West	1	10					1	10
6. Mississauga Halton	3	18					3	18
7. Toronto Central	2	16					2	16
8. Central	1	3			1	4	2	7
9. Central East			1	1	1	3	2	4
10. South East			1	3	2	4	3	7
11. Champlain	4	33	2	24			6	57
12. North Simcoe Muskoka	1	10	2	11			3	21
13. North East	2	20					2	20
14. North West							0	0
<b>TOTALS</b>	<b>26</b>	<b>212</b>	<b>7</b>	<b>49<sup>3</sup></b>	<b>4</b>	<b>11</b>	<b>37</b>	<b>272</b>

<sup>1</sup> MOH RH means funding from the 2005 MOHLTC announcement of 34 residential hospices

<sup>2</sup> LHIN funded means LHIN funding other than from the 2005 MOHLTC residential hospice announcement

<sup>3</sup> Seven sites with 49 beds

### List of Open Residential Hospice including funding source

LHIN	Residential Hospice or Project Name	Location	Funding Source			
			Total Beds	MOH RH	LHIN	Unfunded
1	Hospice of Windsor & Essex County	Windsor	8	8		
1	St. Joseph's Hospice of Sarnia Lambton	Sarnia	10	10		
2	VON Oxford Sakura House	Woodstock	10	10		
2	Grey Bruce Residential Hospice	Owen Sound	6	6		
2	St. Joseph's Hospice London	London	10	10		
3	Lisaard House	Cambridge	6	6		
3	Hospice Wellington	Guelph	10	10		
4	Emmanuel House	Hamilton	10		10	
4	Carpenter Hospice	Burlington	10	10		
4	Stedman House	Brantford	6	6		
4	Bob Kemp Hospice	Hamilton	10	10		
4	Hospice Niagara	St. Catharine's	10	10		
4	McNally House Hospice	Grimsby	6	6		
5	Bethell House (Hospice Caledon)	Inglewood	10	10		
6	Darling Home For Kids (pediatric)	Milton	2	2		
6	Ian Anderson House	Oakville	6	6		
6	Dorothy Ley Hospice	Etobicoke	10	10		
7	Kensington Hospice	Toronto	10	10		
7	Emily's House (pediatric)	Toronto	6	6		

8	Hill House Hospice	Richmond Hill	3	3			
8	Matthews House Hospice	Allison	4			4	
9	The Bridge	Warkworth	3			3	
9	SIRCH Hospice	Haliburton	1		1		
10	Hospice North Hastings	Bancroft	2			2	
10	Heart of Hastings	Madoc	2			2	
10	Hospice Prince Edward	Picton	3		3		
11	Hospice Care Ottawa - May Court Site	Ottawa	9	9			
11	Roger's House (pediatric)	Ottawa	8	8			
11	Hospice Renfrew	Renfrew	6	6			
11	Hospice Cornwall	Cornwall	10	10			
11	Hospice Care Ottawa - West Site	Kanata	10		10		
11	Ottawa Mission Hospice	Ottawa	14		14		
12	Hospice Simcoe	Barrie	10	10			
12	Hospice Huntsville	Huntsville	5		5		
12	Campbell House (Hospice Georgian Triangle)	Collingwood	6		6		
13	Algoma Residential Community Hospice	Sault Ste. Marie	10	10			
13	Maison Vale Inco Hospice	Sudbury	10	10			
			<b>TOTAL BEDS</b>	<b>272</b>	<b>212</b>	<b>49</b>	<b>11</b>
			<b>TOTAL SITES</b>	<b>37</b>	<b>26</b>	<b>7</b>	<b>4</b>

Table 3 List of Open Residential Hospices

### Residential Hospice Sites Under Construction

There are two residential hospice sites under construction: in Kitchener (LHIN 3 Waterloo Wellington) and Barry's Bay (LHIN 11 Champlain). Innis Free House will be a 10 bed facility funded by the LHIN and planned to be open in 2015. The Madawaska Project will be a two bed facility funded by the LHIN and planned to be open in 2015. The six bed site in Collingwood (LHIN 12 North Simcoe Muskoka) opened August 4, 2014 so has been moved to the Open Residential Hospices.

LHI N	Planned Opening	Residential Hospice or Project Name	Location	MOH RH Funded	LHIN Funded	Unfunded	Total Beds
3	2015	Innis Free House	Kitchener		10		10
11	2015	Madawaska Project	Barry's Bay		2		2
				<b>TOTALS</b>		<b>12</b>	<b>12</b>

Table 4 Hospice Sites Under Construction

### Residential Hospice Sites in Planning and Development

Table 5 shows a breakdown by LHIN and known funding source for 20 sites in planning (169); the four sites planning expansions (18 beds in total); and the two sites (12 beds) currently under construction (Innis Free House in LHIN 3 Waterloo Wellington, Madawaska Project in LHIN 11 Champlain). Table 6 shows a summary by LHIN.

Table 5 and 6 are intended to reflect a snapshot of the residential hospice landscape in Ontario and which communities are currently active and engaged in planning for residential hospice services. It is acknowledged that some communities may have initiated their planning process

without having first established LHIN support. It is further noted that planning to date has been largely locally driven, and may or may not have been informed by the population benchmarks and integrated service considerations highlighted in the Residential Hospice Working Group Report *Strengthening Ontario's End-of-Life Continuum: Advice Regarding the Role of Residential Hospices*.

The **MOH RH Funded** column reflects MOHLTC funding that is available for residential hospices. LHINs in consultation with the local community may not be utilizing this funding for residential hospice expansion at this time. LHINs in consultation with the local community may re-profile this funding for other palliative care services that address local needs.

The **Unfunded** column reflects beds that are in planning without formal LHIN support at present.

The projects that are in planning are those known to HPCO as of August 1, 2014.

HPCO estimates that there are between five and 10 additional projects at some level of planning at a local community level but no organization has sent details to HPCO. The estimate is based on conversations with individuals who have contacted HPCO for information on building a residential hospice.

LHI N	Planned Opening	Residential Hospice or Project Name	Location	MOH RH Funded	LHIN Funded	Unfunded	Total Beds
1	2015	Hospice in Chatham	Chatham		10		10
1	2015	Hospice in Leamington	Leamington		10		10
2	2017	Stratford Project	Stratford			6	6
2	2017	EXPANSION Residential Hospice of Grey Bruce	Owen Sound			4	4
3	2015	Innis Free House (under construction)	Kitchener		10		10
4	2015	EXPANSION Stedman Community Hospice	Brantford			4	4
6	2017	Heart House Hospice	Mississauga	10			10
7	Undetermined	Toronto Project	Toronto			10	10
7	2015	EXPANSION Emily's House (pediatrics)	Toronto			4	4
8	2016	Toronto Commandery Hospice	Toronto	10			10
8	2016	York Regional Residential Hospice	Newmarket	10			10
8	2016	Hospice Vaughan	Woodbridge			10	10
8	2017	Central LHIN "South" location	TBD			10	10
8	2016	EXPANSION Matthews House	Allison			6	6
9	Undetermined	Durham Region Hospice Project	Oshawa	10			10
9	2017	Hospice Peterborough	Peterborough	10			10
9	2017	Yee Hong Centre	Scarborough	10			10
10	Undetermined	Hospice Lennox & Addington	Napanee			2	2
10	Undetermined	Hospice Quinte	Quinte			6	6
10	2017	Kingston Project	Kingston	10			10

11	2015	Madawaska Project (under construction)	Barry's Bay	2		2
12	2016	Port Carling Hospice Project	Port Carling		6	6
13	2015	Nipissing Serenity Hospice	North Bay		10	10
13	2015	Timmins Hospice Project	Timmins		6	6
14	Undetermined	Undetermined	Undetermined	10		10
TOTALS				80	32	84
						196

Table 5 Planned Hospice Sites by Opening Dates and Location

LHIN	MOH RH Funded		LHIN Funded		Unfunded		Total	
	Sites	Beds	Sites	Beds	Sites	Beds	Sites	Beds
1. Erie St. Clair			2	20			2	20
2. South West					1	10 <sup>1</sup>	1	10
3. Waterloo Wellington			1	10			1	10
4. Hamilton Niagara Haldimand Brant						4 <sup>2</sup>		4
6. Mississauga Halton	1	10					1	10
7. Toronto Central					1	14 <sup>3</sup>	1	14
8. Central	2	20			2	26 <sup>4</sup>	4	46
9. Central East	3	30					3	30
10. South East	1	10			2	8	3	18
11. Champlain			1	2			1	2
12. North Simcoe Muskoka					1	6	1	6
13. North East					2	16	2	16
14. North West	1	10					1	10
	8	80	4	32	9	84	21	196

Table 6 Summary of Planned Openings by LHIN

<sup>1</sup> Includes one existing site that is planning to add four beds

<sup>2</sup> Includes one existing site that is planning to add four beds

<sup>3</sup> Includes one existing site that is planning to add four beds

<sup>4</sup> Includes one existing site that is planning to add six beds

## Residential Hospice Costs and Funding

### Capital Costs and Funding

10 bed hospices incurred capital costs ranging from \$3 million to \$5 million. Standalone facilities with up to six beds incurred constructions costs that range from \$500,000 to \$2,000,000. Residential hospices raised their own capital. Capital construction and equipment cost was not provided by the Government of Ontario with the exception of one-time grants to 16 locations totaling \$23.9 million in fiscal 2006/2007 and 2007/2008. The locations that received the grants had construction or capital campaigns well underway. The grants were used at the discretion of the hospice organization with some using the funds for capital costs and while others used the grants to support operating costs after opening.

Residential hospices have raised over \$100 million for capital through private donations. The 34 residential hospices currently open raised over \$88 million in capital for construction costs.

**Operational Funding**

In 2010, HPCO worked with all of its residential hospice directors to develop a standard operating budget for a 10 bed hospice. The budget arrived at was \$1.6 million annually. Nursing and personal support salary and benefit costs totaled \$900,000. MOHLTC funding from inception has been restricted to nursing and personal support salary costs. In 2011, MOHLTC increased funding from \$58,000 per bed to \$90,000 per bed. Since 2011, HPCO has adjusted the standard budget for inflation and it is now \$1.67 million. Six bed facilities have an average operating budget of \$1.1 million and three bed facilities \$550,000.

All general medical supplies, equipment, furniture and fixtures, patient food, linens, psychosocial care, spiritual care, bereavement support; facilities operating expense such as maintenance, housekeeping, and administration are funded from private donations and fundraising activities.

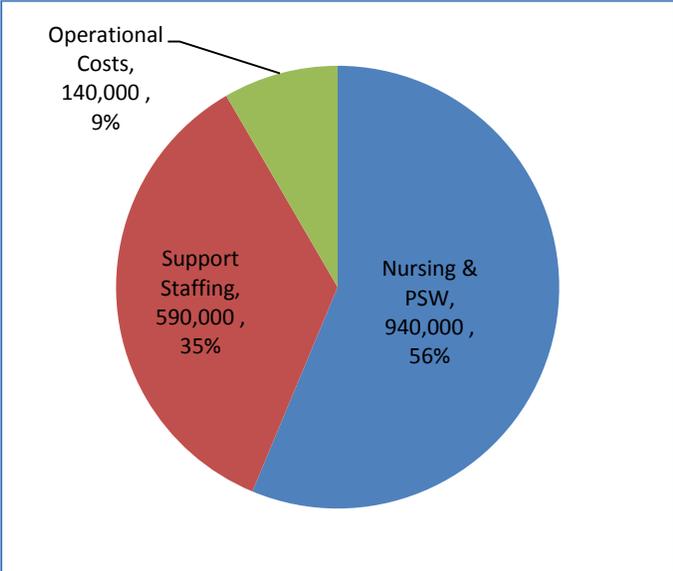


Chart 4 Standard Expenditure for a 10 Bed Hospice

A 10 bed hospice must raise on average, \$770,000 per year or 46% of their operating budget.

A six bed hospice must raise on average, \$560,000 per year or 51% of their operating budget.

A three bed hospice must raise on average \$280,000 or 51% of their operating budget.

The specified per bed rate from MOHLTC is \$90,000 per bed per year for adults and \$134,000 for pediatrics. In some base stabilization increases were passed onto the hospices and as a result some are funded at rates of \$92,000 per bed.

**Staffing**

**Nursing and Personal Support Staff**

HPCO Community Residential Hospice Standard calls for an onsite Registered Nurse 24/7. The majority of residential hospices operate with the staffing model. Registered Practical Nurses and Personal Support Workers are also part of the team and their staff levels vary by shift. For example, a day shift may have an RN, RPN, and PSW, an evening shift may have an RN, and two PSWs, overnight may have an RN and a PSW. Some facilities use an RN and RPN 24/7 with PSWs on swing shifts. This staffing is funded by MOHLTC/LHIN.

MOHLTC provides funding to residential hospices for nursing and personal support services. There are two options for the flow of funding. Hospices may: a) Receive a funding envelope to independently employ nursing and personal support services, with an accountability agreement through the CCAC; or b) Receive nursing and personal support staff through CCAC-contracted service providers.

Of the 33 MOH/LHIN funded sites, 30 use model A and receive a funding envelope. Three sites use model B and received nursing and personal support workers through CCAC contact service providers. One of the two manages the nursing staff while the other two allow the contracted agency to manage the nursing and personnel support staff.

Although the Standard calls for a Registered Nurse onsite 24/7, four smaller residential hospices (3 beds or less) are using a model of care whereby the CCAC provides nursing visits to the hospice patients as required and based on the level of visits that an end-of-life client would receive in a private residence.

One hospice site that opened in August 2013 is designated as a demonstration project by its LHIN and has an agreement in place with the CCAC to provide overnight nursing should the patient require it. HPCO is amenable to modifying our Standard to accommodate this model of care for facilities with less than five beds, and providing that level of care agreement are in place with the CCAC and adequate risk management is in place.

Community Care Access centres may provide the following services:

- PSW support
- Nursing visits – usually a minimum of once daily, more often as deemed appropriate by the nurse, physician and staff, and authorized by the CCAC. A visit is to a maximum of 60 minutes.
  - The visiting nurse is responsible for all medication preparation and administration; family may assist and PSWs may be delegated to administer medication under the supervision of the visiting nurse.
  - The visiting nurse is required to be available on call 24/7 to attend to all nursing/medical care and issues
  - The visiting nurse is expected to provide all other nursing interventions included in the patient care plan.
  - Supplies including mouth swabs, dressings, catheter supplies, disposable incontinent products, medication administration supplies, other medical products as required.
  - Medications administered via pump and in symptom response kit
  - Equipment if required

Physicians

- The resident's family physician continues to provide care if desired. However, if the resident's family physician is unable or unwilling to provide care in the hospice, care will be transferred to a local palliative care physician.

### **Support Services and Administrative Staff**

Support staff varies by the size of the hospice and many include the Executive Director, Care Coordinator, Medical Director, and staff that provide volunteer coordination, community relations, administrative support, housekeeping, maintenance, food services coordination, psychosocial services and complementary therapies. A Medical Director is typically a 0.2 FTE position responsible for

consultations and in some cases takes over care if the patient has no family physician or the family physician has opted not to follow the patient into palliative care. One of the distinguishing aspects of residential hospice is the provision of psychosocial support to patients and family members. This support includes professional anticipatory grief and bereavement counseling, spiritual supports, and group counseling. These services are in general, provided on site when needed because staff is present on site and available when needed. Trained volunteers who are under the supervision of the professional staff often augment these services.

### **Use of Volunteers**

Volunteers are used extensively in residential hospices for administrative support such as reception, greeting, assistance with food preparation, grounds maintenance, companionship for patients, fundraising, and special events. Sometimes complementary therapists volunteer their services for patients and families, fundraising. In general, volunteers in a residential hospice do not provide direct patient care such as lifts and transfers, assistance with bathing, toileting and personal care. While visiting in-home hospice volunteers are trained and may provide such care in a patient's private residence, a residential hospice is not a private residence and liability issues preclude volunteers from performing this care in a healthcare facility. Larger residential hospices (six beds or more) generally do not permit volunteers to perform direct patient care services.

Smaller hospices (five beds or less) do train volunteers to provide assistive care to the residents and must complete the HPCO 30 hour hospice volunteer training course. On completing the course, additional hands-on training is provided on repositioning patients, bathing, mouth care, skin care, changing incontinent products, changing an occupied bed and documentation guidelines. New Volunteers are initially paired with an experienced Volunteer, working in partnership until they have attained a comfort level to work independently

Regardless of professional designation, volunteers in the Visiting Hospice Service will not engage in "controlled acts"\* nor accept delegation of a control act\* from a nurse, including:

- Prescribing, dispensing, selling or compounding a drug as defined in the Drug and Pharmacies Regulation Act
- Administering a substance by injection or inhalation (e.g. adjusting oxygen level, putting oxygen mask on/off the service recipient, turning oxygen machine on/off)
- Putting an instrument, hand or finger into an artificial opening in the body (e.g. suctioning, tube feeding)

\*(Regulated Health Professions Act, 1991, s. 27.(2))

### **Patient Acuity**

When the first residential hospices opened in the late 1990's, the acuity of patients admitted was lower than today and could be managed within the scope of practice of a Registered Practical Nurse. With the implementation of HPCO's Standard and the requirement for 24/7 Registered Nursing, the acuity of patients has increased significantly and matches the skill level of the hospices highly trained Registered Nursing Staff. The majority of the hospices report that their typical patient has advanced illness, often with complex pain and symptom management challenges and are not low acuity frail patients.

Small rural sites report anecdotally that the acuity level of the patients they admit is not high and that many are frail, elderly individuals who cannot be cared for at home. This is an important factor that must be considered when evaluating alternate models of care.

**Corporate Structures**

The majority of residential hospices are independent corporate entities governed by a board of directors. The breakdown of corporate structures of open residential hospices is shown in table 8 and planned residential hospices in table 9.

Corporate Structure	Number of Sites
Independent Corporation	30
Subsidiary/Program of a LTC Organization	1
Subsidiary/Program of a CSS Organization	5
Subsidiary of Hospital	1

Table 8 Governance Structure of Open Sites

Corporate Structure	Number of Sites
Independent Corporation	12
Subsidiary/Program of a LTC Organization	3
Subsidiary/Program of a CSS Organization	3
Subsidiary of Existing Residential Hospice	2
Planned Structure Unknown	1

Table 9 Governance Structure of Sites Under Construction and Planned Sites

**Geographic Location**

HPCO uses the definition of rural adopted by the Rural and Northern Health Care Panel in their 2010 report *Rural and Northern Health Care Framework/Plan, Stage 1 Report* which defines rural as, “communities in Ontario with a population of less than 30,000 that are greater than 30 minutes away in travel time from a community with a population of more than 30,000.”

74% of operating residential hospices and 87% of beds are located in urban communities. Table 10 shows the rural-urban split of existing hospices and table 11 shows the split for planned hospices.

	Sites	Beds	% Sites	% Beds
Rural	10	38	27%	14%
Urban	27	238	73%	86%

Table 10 Existing Residential Hospices by Geography

	Sites	Beds	% Sites	% Beds
Rural	8	56 <sup>1</sup>	38%	29%
Urban	13 <sup>2</sup>	13 <sup>3</sup>	62%	71%

Table 11 Planned Residential Hospices by Geography

<sup>1</sup> Includes one existing site that is planning to add four beds and one planning to add six beds

<sup>2</sup> Includes one 10 bed site currently under construction

<sup>3</sup> Includes the 10 beds currently under construction and one existing site planning to add four beds

### **Hospices as Regional Hubs and Centres of Excellence**

Several residential hospices are emerging as regional hubs/centres of excellence for community based hospice palliative care. These hospices have a range of client service and health care educational components including:

A range of HPC programs that may include:

- Residential beds
- Visiting Hospice Service (in-home volunteers)
- Day Hospice Program
- Integrated Wellness Program for patients and caregivers
- Spiritual, Psychosocial, and Bereavement Programs

Partnerships with medical schools and colleges to offer teaching programs and residencies

- Physicians, nurses, personal support workers, social workers, counselors, etc.

A focus on research by staff and through partnerships with researchers focused on hospice palliative care

These hospices may act as a regional resource by:

- Hosting or managing interdisciplinary outreach team(s)
- Hosting or managing Palliative Pain and Symptom Management Consultants (PPSMC)
- Hosting or managing a Palliative Care Education Program
- Support hospice palliative care capacity building initiatives in their communities e.g. building caregiver capacity through allied community support services
- Offering back office support for smaller agencies (IT, HR, finance, etc.)
- Allowing staff, where appropriate, to provide expertise to other community based hospice palliative care providers

## 4.2 Residential Hospice Utilization Data

### 2012-2013 HPCO Residential Hospice Year-End Statistics

Please note that these statistics are for adult beds only. Inclusion of pediatric beds would skew the numbers because the patterns of hospice use for pediatrics are different from adults. Q2 stats for the current year will be compiled by December 5, 2013.

#### Residential Hospice Statistics April 1, 2012 to March 31, 2013 - All Locations

<b>Reporting</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
# of hospices reporting	19	17	11.8%
Total beds reported	159	144	10.4%

<b>Hospice Profile</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
# of hospice reporting	19	17	11.8%
# of 10 bed sites	11	10	10.0%
# of 9 bed sites	1	1	0.0%
# of 8 bed sites	1	1	0.0%
# of 6 bed sites	4	4	0.0%
# of 5 bed sites	1	0	
# of 3 bed sites	1	1	0.0%

<b>Patient Demographics</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
# of patients aged 18 to 54	736	622	18.3%
# of patients aged 65 +	2095	1693	23.7%
# of pts admitted with Cancer	2384	1951	22.2%
# of pts admitted with non-malignant diagnosis	447	364	22.8%

<b>Referrals &amp; Admissions</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
# of referrals	6287	5142	22.3%
# assessments conducted	3618	2732	32.4%
# of admissions	2831	2315	22.3%
# of pts admitted from home	1516	1263	20.0%
# of pts admitted from hospital	1254	964	30.1%
# of pts admitted from other	61	88	-30.7%
% of pts admitted from home	53.5%	54.6%	-1.8%
% of pts admitted from hospital	44.3%	41.6%	6.4%
% of pts admitted from other	2.2%	3.8%	-43.3%
% of assessed individuals that were admitted	78%	85%	-7.7%

<b>Bed Usage</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
Total bed days available	58035	51030	13.7%
Total bed days used	46939	41556	13.0%
Occupancy Rate	80.9%	81.4%	-0.7%
total bed days used by pts admitted from home	25770	21731	18.6%
total bed days used by pts admitted from hospital	20206	18852	7.2%
total bed days used by pts admitted from other	963	1240	-22.3%
Average lengths of stay (LOS) all patients	19	17.3	8.3%
Average LOS when admitted from home	18	16.3	9.5%
Average LOS when admitted from hospital	20	19.1	3.9%
Average LOS when admitted from other	10	9.1	12.2%

<b>Discharges</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
Total discharges	2670	2238	19.3%
# discharges deaths	2566	2164	18.6%
# discharges to other locations	104	74	40.5%
% of deaths in hospice	96.1%	96.7%	-0.6%

<b>Throughput &amp; Turnover</b>	<b>2012/2013</b>	<b>2012/2011</b>	<b>% Change</b>
Throughput (# discharges/# of beds)	16.8	15.5	8.0%
Bed Turnover Interval (available bed days - pts days in period) /discharges	4.16	4.23	-1.8%

## CCAC Services Provided in Residential Hospices

The following table provides expenditure and utilization statistics for CCACs providing nursing and personal support services to residential hospices. Year to year variances in expenditures and utilizations can be attributed to the absence of uniform reporting and of a standardized method of allocating services to the appropriate cost centres amongst CCACs.

Type of Service	Client Services Expenses			Individuals Served			Visits Face-to-Face and Non Face-to-Face, In-House and Contracted Out			Hours of Care In House and Contracted Out		
	2012/13	2011/12	2010/11	2012/13	2011/12	2010/11	2012/13	2011/12	2010/11	2012/13	2011/12	2010/11
<b>Nursing Visits Functional Centre</b>	\$2,051,022	\$2,529,268	\$3,140,165	66,606	71,240	46,585	2,051,022	2,800,832	3,502,482			
<b>Nursing Shift Functional Centre</b>	\$12,473,836	\$11,815,345	\$7,878,052	3,326	3,150	1,812				320,837	282,446	185,427
<b>Combined Personal Support and Homemaking Services Functional Centre</b>	\$4,978,594	\$4,648,793	\$3,029,405	3,500	3,083	2,375				215,200	214,151	155,703

Source: Ontario Healthcare Financial and Statistical Database (OHFS) – Comparative Report

## 4.3 Literature Review: Economics of End of Life Care

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Current economic evidence indicates that palliative care may be cost saving. Most reports stress the potential cost savings or cost avoidance for the health care system.<sup>59</sup> There are, however, important limitations related both to methodologies and to knowledge translation.<sup>60</sup> <sup>61</sup> <sup>62</sup> Very few studies were identified that focused specifically on costs and resource utilization of institutional hospices<sup>1</sup> compared to palliative care in alternative settings, such as home or hospital. Cost-effectiveness studies were even fewer: only one of 46 cost and health care utilization studies that were included in a 2013 comprehensive literature review was a cost-effectiveness analysis.<sup>63</sup> No literature was identified specifically for residential hospices.

Based on the overall findings, a further rigorous health economics research can help to better meet patient and family needs in the context of where they live and improve the quality and access to care.<sup>64</sup>

### *Current State of Knowledge Related To End of Life Costs*

Patients in the last year of life are the most expensive in the healthcare system, costing Canadians an estimated \$11 billion, where hospital costs comprise over 70% of end of life care<sup>65</sup> with approximately 20 to 30% of all health care expenditures are spent on patients in their final year. Based on Ontario specific research studies:

- The average health care cost to the health care system for all Ontario decedents in their last year of life was \$49,267.66
- 49.5%, 20.2%, and 30.3% of this cost was consumed in the last 3, 3-6, and 6-12 months of life, respectively.
  - During the last 3 months 59.8% was consumed by in-patient hospital costs, followed by: continuing care (20.0%), physician services (10.4%), outpatient services (3.7%), drugs (3.4%), and emergency department (2.8%).
  - Between 3-6 months and 6-12 months, proportion of inpatient services decreased to 37.2% and 29.7%; while the proportion for continuing care rose to 31.9% and 36.4%, respectively.
  - Over the last 12 months before death, the overall top 3 cost sectors were inpatient services (46.1%), continuing care (27.4%), and physician services (10.5%).
- Among decedents, 24% used long-term-care (LTC) and 60% used home care, at an average cost of \$34,129 and \$6,988 among users, respectively. Inpatient care was incurred by 74% of decedents, at an average cost of \$30,255 <sup>67</sup>
- On average, the cost of dying in a chronic care facility is \$36,000 compared to \$16,000 to die at home.

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<sup>1</sup>Various names were used for different types of palliative care. No literature was identified that used specifically the term “residential palliative care”, however, for the purposes of this overview, ‘institutional hospices’ appear to be the closest proxy for ‘residential’ palliative care.

- 72% of end-of-life health costs were for acute care services (excluding ICU stays) with an average of \$25,000 per patient cost.<sup>68</sup>
- A residential hospice bed costs \$439 per day to operate.
- A shared care model to provide enhanced end-of-life care identified costs for all patient-related services to be \$117.95 per patient day (in a rural setting in Southern Ontario).<sup>69</sup>
- Monthly informal caregiver expenditures can amount to \$25,000 and account for lost wages and leisure and patient health costs.

A 2004 Manitoba study found that decedents – 1.1% of the population – consumed 21.3% of health care costs in the final six months of life.<sup>70</sup> Annual health care expenditures for terminally ill patients are on average five times higher than non-terminal patients. In a 2009 Saskatchewan study, the average monthly per person cost to the health care system increased from \$1,373 12 months before death to \$7,030 for the last 30 days; when user fees were included, the average costs were \$1,641 and \$7,420 respectively.<sup>71</sup>

Studies in the US have found that Medicare, the health insurance program for the elderly, spent nearly 30 percent of its budget on beneficiaries in their final year of life (or about \$88 billion). Slightly more than half of Medicare dollars were spent on patients who died within two months. From 1992 to 1996, mean annual medical expenditures (1996 dollars) for persons aged 65 and older were \$37,581 during the last year of life versus \$7,365 for non-terminal years. Mean total last-year-of-life expenditures did not differ greatly by age at death. Last-year-of-life expenses constituted about 25% of all medical expenditures from all sources.<sup>72</sup>

One of the key cost drivers for end-of-life care is the type of care that people receive before dying. For example, up to 20% of all deaths in the US occur during or shortly after a stay in resource-demanding intensive care units.<sup>73</sup> A Canadian study found that the cost of care for patients with terminal illnesses increased from the fifth to the last month of life due largely to the cost of inpatient care.<sup>74</sup> In Ontario, according to ICES and MOH analysis, palliative patients and people who die represent a large proportion of patients within the top 10%, 5% and 1% highest cost health care user groups.

Families also face significant costs. A 2010 study by Guerrier and colleagues assessed the societal costs of home-based palliative care and examined the socio-demographic and clinical factors that account for variations in costs over the course of the palliative trajectory. The total mean monthly cost of care per patient was about \$25,000.<sup>75</sup> This high cost was due in large part to the detailed accounting of caregiver's lost wages and leisure. These costs made up \$17,453 – or more than two-thirds of the \$25,000 monthly total. Other costs included \$6,400 per month per patient in health care system costs, \$172 in third-party insurer costs, and \$698 in patient or family out-of-pocket expenses. There was variation in costs across individuals. Costs were greater for patients who: had lower physical functioning; lived with someone; and when the patients approached death. Information highlighting the variation in costs across individuals may aid policy makers and managers in deciding how to allocate resources.

### ***Current State of Economic Evidence Specific to Residential Hospices***

Although awareness about the importance of cost component is increasing, it has been often overlooked in palliative care studies, especially for residential palliative care.<sup>76</sup> In most jurisdictions, residential hospices comprise a small but important element within a broader community-based hospice palliative care program. Information on relative costs and effectiveness of palliative care in various settings, such as home-based vs. hospice-based, is limited. The terminology and definitions vary across studies, and in a number of cases, adequate description of the interventions being studied is limited, making comparisons even more difficult.

According to HPCO business case, provincial average daily cost of care in a residential hospice bed has been estimated at \$436. This is less than care in some hospital-based settings such as ALC beds (estimated at \$850 per day). However, insufficient information exists on the variation in residential hospice per diems, the variation in hospital per diems depending on facility and care setting (e.g. palliative unit; ICU; ALC bed; general ward etc); the relative patient outcomes by setting; indirect costs to patients and their caregivers; and a description of interventions to allow comparisons across studies and prevent comparison of findings from studies that include different services, resource utilization and cost structures. This information is necessary for achieving optimal patient outcomes more cost-effectively in a preferred care setting.

### ***Economic Literature Review of Palliative Care in General***

A 2013 systematic review of literature on costs and cost-effectiveness of palliative care concluded that overall, palliative care was most frequently found to be less costly relative to comparator groups.<sup>77</sup> A total of 46 papers, published from 2002 to 2011, met the criteria for inclusion in this systematic review. The main focus of these studies was on direct costs with little focus on informal care or out-of-pocket costs. The overall quality of the studies was mixed and they involved significant limitations.

Only one of the 46 studies that were found to be eligible for inclusion was a cost-effectiveness analysis.<sup>78</sup> It looked at short-term palliative care in multiple sclerosis. Patient outcomes were measured on the Palliative Care Outcome Scale (POS-8) and caregivers' burden was measured using the Zarit Carer Burden Inventory (ZBI). The baseline estimates indicated that the intervention was cost-saving, with equivalent outcomes on the POS-8 scale and improved outcomes on the ZBI. When sensitivity analysis examined uncertainties, the palliative care group had lower costs and better outcomes than the control group 33.8% of the time for the POS-8 measure. For the ZBI measure, the sensitivity analysis indicated that the palliative care group had lower costs and better outcomes 47.3% of the time.

A 2007 report of an international think tank came to similar conclusions as the above 2013 literature review.<sup>79</sup> It stated that although many studies provided insight into the *economics of palliative care*, most were cost-minimization studies and not full economic evaluations. Therefore, they provided very little information about the costs of palliative care in relation to

outcomes. The available studies suggested that palliative care is cost saving. However, caution was recommended, as the quality of the evaluations was found to be poor, the methods were heterogeneous, informal costs were rarely captured, and there were problems with analysis, particularly relating to costs being very different depending on the time closer to death<sup>80</sup>.

An important component of a full economic evaluation study, such as a cost-effectiveness study, is the evidence on effectiveness of interventions. This evidence is especially meaningful when it is acquired in a local context. A 2008 Ontario study found that a shared care model<sup>2</sup> designed to enhance family physicians' ability to deliver quality palliative home care, particularly in community-based settings, improved communication, effective interprofessional collaboration, and the capacity to deliver palliative home care, 24 hours a day, 7 days a week, to end-of-life patients in the community<sup>81</sup>. "Later resource utilization and economic analyses of 95 study participants in this program indicated that Community Care Access Centre and Enhanced Palliative Care Team-based homemaking and specialized nursing services were the most frequented offerings, followed by equipment/transportation services and palliative care consults for pain and symptom management. Total costs for all patient-related services (in 2007 \$CAN) were \$1,625,658 or \$17,112 per patient or \$117.95 per day in program."<sup>82</sup>

### ***Comparison across different types and settings of palliative care***

The characteristics of the setting – as well as those of the patients – influence the cost of palliative care. Hospice use has grown considerably over the last decade, especially among individuals in institutional settings.<sup>83</sup> Five publications were identified that focused on comparison across different types and settings of palliative care.

Policymakers have invested in home-based interventions, specifically in expert-consult teams (also known as specialist palliative care teams) throughout Ontario. Based on results of a 2013 Ontario study by Seow and colleagues,<sup>84</sup> a community-based palliative care provided by expert-consult teams reduced end-of-life patients' late-life acute care utilization compared to a usual community-based palliative care. This has implications to health system efficiency and cost reductions. The relative risk of being in hospital in the last two weeks of life was reduced by a third when exposed to a team versus usual care<sup>3</sup> (31.2% of the group exposed to expert-consult team-care was in hospital in the last 2 weeks of life compared to 39.3% of the unexposed group). The same reduction in relative risks was observed for ED visits (28.9% of the group exposed to expert-consult team-care had an ED visit in the last 2 weeks of life compared to 34.5% of the unexposed group). A 50% reduction in relative risk of dying in hospital was

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<sup>2</sup> Family physicians in 3 group practices (N = 21) in Ontario's Niagara West region collaborated with an interprofessional palliative care team (including a palliative care advanced practice nurse, a palliative medicine physician, a bereavement counselor, a psychosocial-spiritual advisor, and a case manager) in a shared-care partnership to provide comprehensive palliative home care.

<sup>3</sup> Without expert-consult teams, the majority of home-based palliative care in Ontario is delivered by the public homecare system – referred to as 'usual care' in Hsien Seow's study.

associated with being exposed to an expert-consult team compared to usual care (16.2% of exposed patients died in hospital compared to 28.6% of patients of the unexposed group).

A 2011 U.K. study by Higginson and colleagues found that early (“fast track”) palliative consultation by a multi-professional palliative care team can reduce costs and use of other health services for patients with severe multiple sclerosis (MS) in multiple settings, including home, outpatient clinic, nursing home or hospital.<sup>85 86</sup> Service costs for the “fast-track” patients, including inpatient care and informal care, were £1,789 lower per patient compared to usual care (later stage palliative consultation) patients. “Fast-track” patients also made less use of other resources: usual care patients were more likely to consult with their general practitioner, receive help from family or friends, and to be admitted to or seen at hospital.<sup>87</sup>

A 2007 study by Stevenson compared resource utilization, length of enrollment and patient characteristics for home hospice patients to institutional hospice patients in the U.S.<sup>88</sup> Institutional hospice users were significantly more likely to receive certain types of services such as physician services and prescription medicines, but had significantly shorter average length of enrollment than home hospice users. Institutional hospice users were older than home hospice users; more likely to be female, unmarried, and dually eligible for Medicare and Medicaid; and more likely to have primary diagnoses other than cancer.

A 2007 study by Tamir and colleagues compared costs of patients who received home specialized palliative care services to patients who received home non-specialized palliative care services in Israel.<sup>89</sup> Average health services cost per person in the specialized care group were 31% lower than in control group over the last year of life.

A 2006 study by Tibi-Levy and colleagues compared both costs and utilization for rehabilitation palliative care and acute palliative care units in France.<sup>90</sup> Palliative hospice care was less expensive when delivered in rehabilitation or extended care hospital than in acute care facilities (approximately €388 per day vs. €482).

A 2014 study<sup>91</sup> led by Jinhai Huo, PhD, MD, MPH of patients with metastatic melanoma found that those who spent more time in hospice care lived almost four months longer than similar patients who had little or no hospice care, and that end-of-life costs dropped for those with more time in hospice. Patients with at least four days of hospice lived an average of 10.2 months, while those with no care lived 6.5 months and those who received up to three days of hospice lived 6.1 months. Patients with at least four hospice days had lower healthcare costs in their final three months, with the cost dropping between \$9576 and \$14,680, depending on the calculation method used. Besides the amount of hospice care, only the patient's age made a significant difference in healthcare costs.

The need for palliative care will continue to increase due to three main pressures: first, aging populations; second, fiscal constraints; and finally lower availability and higher opportunity costs of providing informal care for family members due to increased labor market

participation. Currently 8,000 dedicated palliative care services exist in the world.<sup>92</sup> These services are expected to avert higher costs to the wider system.

A 2012 publication by the Canadian Hospice Palliative Care Association indicated that health care systems across Canada are paying more attention to the amount spent on patients during the last months of life due to concerns about escalating health care costs.<sup>93</sup> According to a World Health Organization report, the issue is not the need for more research on palliative care practices but rather the ability to implement what is known to address large and growing unmet needs.<sup>94</sup> Based on a special report by the Economist Intelligence Unit, even if hospice palliative care improves quality and offers efficiencies, improving access will be a challenge.<sup>95</sup>

The literature indicates that there are differences in service use, patient characteristics and length of enrollment across hospice settings and type of palliative care. There is a growing need to analyze the implications of these differences. Many questions about hospice use across settings remain unanswered, including whether agency costs differ in institutional compared to home settings.<sup>96</sup> As policymakers seek to assess the quality and appropriateness of hospice utilization and the methods used for its payment, further empirical work is needed, including how the growing use of hospice in different settings affects options for reform.<sup>97</sup>

Some of the methodological considerations and challenges in the economic evaluation of palliative care include:<sup>98</sup>

- Identifying the variety and types of costs in palliative care
- Measuring the costs of informal care
- Improving methods and tools for measuring outcomes of palliative care
- Methods and tools for soliciting population preferences<sup>99</sup>
- Determining the most appropriate types of economic evaluations for palliative care, for example, whether cost-consequence analysis can be used as a means to capture the multiple outcomes of palliative care
- Identifying the limitations and the value of using the standard measure of effectiveness in cost-effectiveness studies, i.e. the quality adjusted life years (QALYs), in palliative care<sup>100</sup>
- Linking the cost perspectives taken (e.g., health care, social care, families, society) to the relevant levels of decision (e.g., governments, ministries, individual services, user organizations)<sup>101</sup>

Further research, better projections of need and longitudinal analysis to map trajectories in costs alongside outcomes over time would help in policy development and implementation. A closer dialogue between health economists, policy developers and advocates can help to translate the health economics findings into clear messages so that they can better inform the policy options for palliative care. Methods and tools to measure costs and outcomes need to be studied, agreed upon, improved, and standardized among researchers, health economists and policy makers.

## 4.4 Palliative Care-Related Inpatient Bed Capacity: Jurisdictional Scan

Jurisdiction	Inpatient Locations and Capacity
Fraser Valley, British Columbia	<p><i>Approximately 8 residential hospice beds per 100,000 people</i></p> <p>Hospice residences provide a home-like setting, and are often physically attached to a residential care facility, hospital or other type of housing where hospice palliative care is provided on a 24-hour basis.</p> <p><i>Approximately 2 tertiary beds per 100,000 population</i></p> <p>Tertiary beds are available for patients with unstable pain management and symptom control issues or emotional distress. These patients require specialized, frequent, and skilled assessments and interventions over a short period of time and/or require diagnostic tests, complex treatments or invasive procedures.</p> <p>Inpatient care is also available:</p> <p>In hospital: short-stay beds are available on medical units in all Fraser Health hospitals for hospice palliative care patients needing diagnostic tests and treatment. Teams of health professionals specializing in hospice palliative care provide expert advice, consultation and support about hospice palliative care to staff, patients and families. Bed count per population is unknown.</p> <p><i>Funding</i></p> <p>Fraser Health provides basic operating funds for hospice beds. Fraser Health does not provide capital funding for construction of hospice beds.</p>

Jurisdiction	Inpatient Locations and Capacity
United Kingdom	<p data-bbox="296 277 1243 310"><i>Approximately 5 hospice and palliative care beds per 100,000 inhabitants</i></p> <p data-bbox="296 358 1680 578">Patients are admitted to a hospice or palliative care inpatient unit at an early stage of their illness for a short period of intensive care, for example 10 to 14 days, and they will then go home or to another care setting. It could be for rehabilitation after treatment, or to control their symptoms (for example, pain, nausea or vomiting). People may also be admitted to a hospice during the final stages of their illness. There are 266 hospice and palliative care inpatient units in total, and 3538 hospice and palliative care beds in total.</p> <p data-bbox="296 630 695 662">Inpatient care is also available:</p> <p data-bbox="296 708 1696 1008">In hospital: There are palliative care teams that work in hospitals alongside medical and nursing colleagues, and other health and social care professionals. Their role is to support the hospital staff by providing education, training and specialist advice on controlling pain and other symptoms. The team will also provide emotional support to patients and their carers, and will advise staff on planning for when people go home or transfer to another care setting such as a hospice, community hospital or care home. In some hospitals there is a whole team, including doctors, nurses, social workers and chaplains, while in others a single nurse provides the service. These teams will often work closely with their local hospice and may even be part of the hospice.</p> <p data-bbox="296 1057 401 1089"><i>Funding</i></p> <p data-bbox="296 1097 1671 1203">In the UK, £1.6 million is spent on hospice care every day. Adults' hospices in England receive on average 34% of their funding from the government. Children's hospices typically receive 19% of their running costs from the government.</p>
Ireland	<p data-bbox="296 1255 1398 1287"><i>Approximately 3 hospice inpatient beds (specialist palliative care) per 100,000 people</i></p> <p data-bbox="296 1333 1675 1399">Inpatient hospices provide care usually for two to three weeks, after which many patients return home, with their condition either stabilised or improved. Patients will receive treatment to help relieve pain and</p>

Jurisdiction	Inpatient Locations and Capacity
	<p>other symptoms causing discomfort. Bed numbers vary across the regions from 0 - 8.3 beds/100,000 of the population. National Advisory Committee on Palliative Care recommended that there should be ten hospice beds per 100,000 of the population, which has been adopted as government policy by the Republic of Ireland. However, according to the latest report from the Irish Hospice Foundation, just “just two regions – the midwest and northwest – come close to fulfilling government policy.”</p> <p>The hospice inpatient unit is seen as the ‘hub’ of the specialist palliative care service, facilitating the movement of patients to the most appropriate care setting during the course of their illness.</p> <p><i>Approximately 5 palliative care support “level 2” (intermediate palliative care) beds per 100,000 of the population</i></p> <p>Palliative care support beds are non-specialist beds, generally located in community hospitals or nursing homes, which provide an alternative to admission to an acute hospital.</p> <p>Inpatient care is also available in acute care hospitals, community hospitals, private nursing home, and hospice. However, only a quarter of acute hospitals in Ireland have a full specialist palliative care team.</p> <p>There is variation in the availability of services in different regions.</p> <p><i>Funding</i></p> <p>The current budget for specialist palliative care in Ireland is €78 million, representing 0.6% of the total health budget. Hospices receive additional funding through fundraising efforts.</p>
United States	<p>Varies across the country. Inpatient capacity information is not readily available. However, the National Hospice and Palliative Care Organization indicates the following:</p> <p>In 2011, 5,300 hospices programs operated in the United States across all 50 states. The majority of hospices (58%) are free standing/independent agencies. 20% were part of a hospital system, 17% were part of a home health agency, and 5% were part of a nursing home.</p>

Jurisdiction	Inpatient Locations and Capacity
	<p>The report also indicates that 66% of palliative patients die at home, while 26% die in an inpatient hospice facility, and 7% die in an acute care hospital.</p>
New Zealand	<p><i>Estimated 6 beds per 100,000 adult population</i></p> <p>The majority of palliative beds are in inpatient hospices, where people are admitted for symptom management, respite care, and care in the final days of life. The median average length of stay is 8 days in inpatient hospices.</p> <p>Inpatient care is also available in Aged Residential Care facilities as well as hospitals.</p> <p><i>Funding</i> Hospices are partially funded by the government to approximately 50% of their operating costs. The balance is raised through fundraising. All hospital services provide free care.</p>
Australia	<p><i>Estimated 7 beds per 100,000 people (benchmarked for South Australia by 2016)</i></p> <p>Inpatient beds used specifically for palliative care patients may include a variety of configurations and settings including beds in a rural community hospital, designated beds in a teaching hospital or a purpose-built hospice. The current benchmarks assume that as patients are stabilised they will return to more appropriate levels of care-discharge to home under community palliative care providers, transfer to an aged care facility or other sub-acute clinical environments.</p> <p><i>Funding</i> \$113 million was provided from 2009-2013 for Australia’s National Palliative Care Program, which includes community-based supports, palliative medicine, training for providers, and quality improvement of palliative care.</p>

Jurisdiction	Inpatient Locations and Capacity
Catalonia, Spain	<p><i>Approximately 8 palliative care unit (PCU) beds per 100,000 people</i></p> <p>In 2007, four PCUs were located in acute care hospitals, 37 in sociohealth centers, and 22 in nursing homes. In 2005, the average LOS in a PCU was 24 days (range: 9-38 days); 70% of these patients died in a PCU (range: 55% in acute care hospitals to 90% in nursing homes).</p> <p><i>Funding</i> Overall yearly costs are around €52.5 million (2012).</p>
The Netherlands	<p>There are 3 types of residential hospices: 1) high care hospices, 2) almost home houses / street hospices, and 3) palliative care units in nursing home or long term care homes. High care and street hospices rely on government subsidies and funding for care, and donations to charity and volunteers for operating. High care hospices have 8-10 beds with dedicated medical staff and volunteers, street hospices provide assessed hours of care and family doctors keep in contract with their patients. Palliative care units in nursing home have 4-10 beds in existing facilities with a nursing home physician. There are 1250 beds in the Netherlands</p> <p><i>Average of 7.2 palliative care beds per 100,000 people</i></p> <p>This palliative care bed count includes beds that are available in nursing homes, hospitals, and hospices.</p> <p><i>Funding</i> All basic medical costs, including care by General Practitioners, hospital stays and many drugs are covered through a mandatory basic insurance. Supplementary insurance is available to cover additional costs.</p>
Poland	<p><i>Distribution of 1-8 palliative care beds per 100,000 inhabitants (2010)</i></p> <p>There are over 500 palliative care units in Poland and over 130 in-patient units (hospital departments or free standing hospices) comprising approximately 1000 beds. There is large discrepancy in distribution of</p>

Jurisdiction	Inpatient Locations and Capacity
	<p>beds between different provinces e.g. in West Pomeranian 1 and in Great Poland over 8 beds per 100,000 inhabitants. Palliative home care is better developed in bigger cities than in rural areas. The availability of home care differs significantly (35% –90%) in different administrative districts. The aim is to establish at least one home team in one administrative district and one in-patient unit for 1–2 administrative districts depending on local needs.</p> <p><i>Funding</i> Costs of palliative care units are partially covered by the National Health Fund for palliative medicine in-patient units in hospitals and in free standing hospices. Many public and non-public units seek financial support from donations.</p>
Alberta	<p>Edmonton Zone Palliative Care Program and Alberta Health Services’ Palliative and End of Life Care Provincial Framework recommends that there should be 7.7 hospice beds per 100,000 population.</p> <p>Presently Alberta Health Services and Alberta Health and Wellness have formed a provincial working group with the intent to develop a provincial framework and policies for palliative and end of life care for Alberta, which will consider this benchmark throughout its work.</p>
Belgium	<p><i>Belgium has 3.5 palliative care unit (PCU) beds/100,000 population (2009)</i> Patients with very complex palliative care problems can be hospitalised in the PCU. The unit is specialised in symptom control, provides psychological guidance, spiritual and social care and offers bereavement counselling. The ratio of nurses per bed is 1.5 FTE; at least 66% of caring personnel are graduated nurses and at least 66% have had training in palliative care.</p> <p><i>Other Supports Available</i> Belgium is divided into 25 organised Palliative Care Networks with at least one palliative network per community. In each palliative network one mobile palliative home care team is available 24/7 covering the respective geographical area. Every nursing home is required to have the necessary infrastructure to care for and support terminal patients and their next of kin. According to legal regulations every hospital (except</p>

Jurisdiction	Inpatient Locations and Capacity
	<p>pure psychiatric, geriatric or revalidation services) must have a palliative support team with 24/7 on-call duty. Palliative day care centres are complementary to primary home care; a multidisciplinary team with a certain ratio of educated nurses gives patient support and can offer important support to family and informal caregivers.</p> <p><i>Funding</i> Palliative care in Belgium is mainly publicly funded. Patients who wish to die at home, and are expected to have less than 3 months left to live are entitled to receive ‘a palliative care bonus’ of 483.39 a month (indexed in 2009; for a maximum of two months). This bonus is meant to cover medication costs and costs for helping devices (beds, special mattresses etc.). Depending on the setting the different palliative care services will receive funding from the federal government, with their respective communities sometimes topping up costs with private funding.</p>
Victoria Hospice Society	<p><i>Approximately 5 in-patient beds per 100,000 population</i> The in-patient unit is located within a hospital and consists of 7 acute care or assessment beds, 9 long-term care beds, and 1 respite bed. The goal for admission to acute care beds is to provide active symptom management so that patients can go back home. Patients admitted to long term care beds are long-stay patients.</p> <p>Most Victoria Hospice patients receive care in their own homes. An on-call Palliative Response Team (PRT) provides short-term crisis consultation and treatment at home, day or night, for problems that might otherwise require admission to hospital.</p> <p><i>Funding</i> In general, there is no fee for Victoria Hospice services; however, as determined by provincial government policy, there is a daily charge for long term and respite care beds. The society receives half of its annual funding from the local health authority and half from community donations (total budget: \$7 million)</p>

## Summary of Findings

- Delivery models vary with oversight from regional health authorities to state responsibility.
- Funding models are similar with costs being subsidized through a government program/health insurance. In British Columbia, the cost of room and board are the responsibility of the patient.
- Eligibility criteria required patients to be palliative however the definition of palliative varies. In the United Kingdom, eligibility was based on need rather than prognosis so patients would be able to access a residential hospice at any stage of their illness.
- Average length of stay ranged from 12.5 days in Australia to 69.1 days in the United States.
- In two regions, the population benchmark for beds per 100,000 people were identified as 8 beds in Fraser Valley, British Columbia and 6 beds in South Australia.

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
British Columbia	Oversight by regional/provincial health authorities Delivered through various provider models (see section 3.1)	Provincial funding covers most costs of care; patients fund room-and-board (unless having limited financial means).	Cannot be supported in community or residential care; no need for acute care; life expectancy of less than three months; and agrees with the hospice philosophy of care (i.e., palliative not curative)	BC residents with active medical service plan coverage, who are already supported by the hospice palliative care program and BC Palliative Care Benefits Program	Provincial average not identified. 19 days in the Fraser Valley Health Authority (FHA)	8 beds per 100,000 people in Fraser Valley.	Varies by health authority FHA had developed a funding partnership framework requiring specific terms to be met in order to ensure an appropriate and consistent standard of hospice care
Nova Scotia	No free standing RHs in the province. Palliative	Provincial funding covers most costs of care.	Clients may be considered "palliative" when:	Individuals and families who are living with a life-	Not identified.		Through the district health authorities. Eligibility for

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
	<p>consultations/care maybe provided at home, in hospitals or in palliative care units (in hospitals). Oversight through the 9 District Health Authorities.</p>	<p>Patients may have to pay a portion for home care Home Support (such as personal care, respite and housekeeping) (income tested). Palliative Care Home Drug Program covers the cost of medications.</p>	<p>a) their condition has been diagnosed by a physician as terminal with life expectancy of weeks or months; The communication to a Continuing Care Assessor of a person's palliative status, for the purpose of determining eligibility for palliative home care, may happen in a variety of ways including identification by a District level Palliative Care Team, a family physician, etc.</p>	<p>threatening illness, usually at an advanced stage.</p>			<p>palliative home care services established by the NS Department of Health and wellness.</p>

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
			b) active treatment to prolong life is no longer the goal of care; and c) the case management process has determined through assessment that the individual has “end stage” palliative care service needs.				
Quebec	Palliative care is managed and delivered at the regional level.		Patients are identified as palliative based on a set of clinical indicators.	Access to beds in palliative care institutions and hospices is subject to eligibility criteria generally based on survival prognosis. Most require a prognosis of	Not identified.		Generally, MSSS adopts general orientations, sets national objectives, and allocates resources to the local service network development agency. MSSS sets provincial palliative care objectives for the client program

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
				less than two months for a patient to meet their organizational standards.			in question (physical health). These objectives are included in management agreements between MSSS and the development agencies.
United Kingdom	Care typically delivered by charitable hospices, though about 19 percent operated within the National Health Service (NHS)	About 34% of funding (in England) provided by government, with remainder provided by charitable donations from the community free for patients and their carers, family members and friends	Availability is dependent on need rather than prognosis, so can be accessed at any stage of illness, not just end of life	Available to anyone with an advancing and potentially terminal illness, including those with cancer, heart failure and lung disease	Average length of stay in inpatient specialist palliative care is 13.5 days, with about 45% of the persons admitted discharged home		The Care Quality Commission (CQC) is the independent regulator of health and adult social care in England. The CQC registers care services that meets its national standards, inspects them to check that they continue to do so, and takes action if they do not
Ireland						National Advisory Committee on Palliative Care recommended	

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
						one hospice bed per 10,000. Irish Hospice Foundation, <sup>1</sup> reports just "just two regions – the midwest and northwest – come close to fulfilling government policy."	
United States	Provided by government (5%), non-profit (34%), and private, for-profit (60%) health care providers	Medicare Hospice Benefit (MHB) covers approximately 84% of patients, with about 8% funded by private insurance and about 8% funded through other sources (e.g., Medicaid, charity)	-be eligible for Medicare (e.g., US citizen, over 65); -medical certification of terminal illness and six months or less to live; -decline Medicare-covered benefits; and -receive care from a Medicare-approved	Unlike many other jurisdictions examined in this review, hospice patients in the US are most likely (62.3%) to have a non-cancer diagnosis (e.g., dementia, heart disease)	The average length of stay in US hospices was 69.1 days in 2011, while the median length of stay was 19.1 days		Variability in the nature and quality of care has been identified as another area of concern with current regulation and governance of US hospices; Medicare does not collect information on the number, frequency, or duration of visits or which personnel provide which aspects of care to

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
			hospice program.				hospice patients (see Section 5.5).
New Zealand	In New Zealand, what is referred to as “hospice palliative care” may be provided in hospice in-patient facilities, hospital rest homes or in a person's home or place of residence in the community	Hospice care and support is free to all. Most funding comes from the central government with the remainder donated by the community in which the hospice operates	A referral to a hospice or palliative care service is normally made by a person's own GP or hospital doctor, but a referral may also be made by a district nurse	The majority of patients have cancer, but patients with other terminal illnesses also receive care (e.g., heart failure). Patients may be referred as soon as a diagnosis is made, not just at the very end of life	National average not identified. According to one hospice industry association, many patients spend a day or two in hospice for symptom control and pain management, and then they return to their homes where their care is continued		Hospice New Zealand (HNZ) funded by the Ministry of Health to develop standards for palliative care aimed at ensuring consistency of service regardless of locality Quality program developed by NHZ helps hospices to meet these standards (see Section 6.5)
Australia	Planning and delivery of hospice (or palliative) care services in Australia is a State/ Territory responsibility Services are	Funding models vary by state/territory (see Section 7.2) Palliative care services are generally free through Medicare, which	In 2008-2009, 77% of palliative care was for public patients; 16% of these cases were funded by private health insurance and	Approximately 60% of the patients accessing palliative care in all locations had cancer (as their principal diagnosis),	No national information on length of stay for hospice patients could be identified for Australia. Among	Est. 6 beds per 100,000 people (benchmarked for South Australia by 2016)	National Standards Assessment Program (NSAP), a national framework for continuous quality improvement in palliative care Accreditation

Jurisdiction	Delivery	Funding/Cost to Patients	Eligibility Criteria	Patient Groups	Length of Stay	Capacity by Population	Accountability Arrangements
	provided in settings such as the home, nursing homes, residential aged care facilities, palliative care units, hospices and in hospitals	typically covers public hospital and hospice fees. Patients may be asked to pay for equipment for use at home (e.g., special beds, wheelchairs), as well as some supplies and medication	7% by the Department of Veterans' Affairs	while just over 8% had a cardiovascular diseases, 8% had a respiratory system diseases, and the remainder had another principle diagnosis	patients admitted to palliative care in a hospital setting, the average length of stay was 12.5 days.		services for health care providers and facilities involved with palliative care (e.g., Royal Australasian College of Practitioners) are asked to incorporate the national standards in assessments of such care

## 4.5 Models of Care: Residential Hospices

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### *Rural Options for Residential Hospice Care – Observations for the Central East Residential Hospice Working Group<sup>102</sup>*

Below are observations following consultations with key informants in Ontario and Canada, analysis of Hospice Association of Ontario's 2009 questionnaire, review of regional best practices in Canada and international peer reviewed literature on rural palliative care.

- Residential hospices in rural areas have greater chances of success in development, acceptance and integrated service delivery when built upon an existing and sustainable community-based hospice palliative care program or initiative.
- Rural hospice palliative care needs a “whole community” approach: community focused development is the essential issue.
- Policies and procedures are needed -- but working on these at the very outset of a new rural initiative can bog down progress, and therefore are best not developed in detail until the community is effectively ‘growing the program’
- In Australia, where rural palliative care is a national priority, it has been determined that community development of hospice palliative care must also be a facilitative process. In launching the Rural Palliative Care Project, with new funding to be allocated to 36 rural divisions across Australia over 2008-2010, the Australian Government recognizes that effective implementation requires an assigned facilitator who must be someone from within the local community and who is competent to fill the role requirements. The facilitator will be:
  - Required to provide initial leadership in starting the building process and liaising with other potential team members; and,
  - Responsible for bringing the community group together helping it to start its workThe purpose of the funding is to implement and reorient rural palliative care services in order to provide sustainable models of rural palliative care delivery that can be adapted to address the local needs of rural communities throughout Australia. These models will be reviewed in 2010 for examples of best practices in the 36 rural regions.
- Small residential hospices that do try to operate while receiving no funding from the MOHLTC/LHIN, and which rely on volunteers and existing CCAC services, are certainly dedicated and resourceful in attempting to meet the need of their community, and do valuable work. They are unable, however, to adhere to the HAO basic standards for residential hospice care, or to meet expectations of 24/7 nursing care as outlined in the MOHLTC's ‘Residential Hospice: Funding and Accountability Overview’, May 2006
- Not all rural residential hospices need be stand alone buildings like Hospice Renfrew, but can operate as dedicated hospice suites in shared facilities, among other approaches:
  - It has been the Fraser Health (FH) experience that ten beds is the smallest size possible to provide efficient and effective staffing for a dedicated hospice residence,

which is problematic for smaller rural communities. Rural hospice beds are also seen by FH as creating a more appropriate care setting for patients from rural areas who are dying, as well as providing the favourable economics that occur when a shift is made away from acute care.

- In small communities that do not have the population and/or resources to establish a dedicated hospice residence, such as Hope BC with a population of 9,000, two designated, purpose built hospice suites have been established within Fraser Canyon Hospital, an acute care facility with ten beds. FH recommends this model for other communities that are unable to establish a designated hospice residence at this time, but with sustainable operational funding from FH are able to arrange for designated hospice beds within a sub acute unit/ transitional unit or some other suitable locations within an acute care facility.

### ***Residential Hospice Model at Hospice Prince Edward***

Hospice Prince Edward is a pilot project designed around a rural, small scale population. In this model, the hospice has 3 beds with an average length of stay of 20 days. The hospice does not have constant medical support on site. Instead, at some times a nurse has a 30 minute response time in case of need. The pilot is currently going through evaluation.

### ***Trends in Growth, Delivery and Quality of Hospice Care – United States***

Hospice care in the United States is provided by government (5%), non-profit (34%), and private, for-profit (60%) health care providers. Since the mid-1990s, the number of private providers has steadily increased while the number of government and non-profit providers has remained relatively constant. The average length of stay in US hospices increased to 69.1 days in 2011, while the median length of stay was 19.1 days. More than 80% of hospice patients are White/Caucasian, 8.5% are Black/African American, and 8.7% are from other ethnic backgrounds. Most patients die in their own homes (41.6%), though about one quarter (26.1%) die at the hospice, nursing home (18.3%), acute care hospital (7.4%), or residential facility (6.6%).

**Fraser Health, British Columbia**

The chart following summarizes the key components of the differing Fraser Health residential hospice operational models and description of patient need defined by Fraser Health.

	Fraser Health Owned and Operated	Fraser Health Leased and Operated	Contracted Service Provider (CSP)	Hospice Society/ Fraser Health Shared Management
Building	Fraser Health pays for all capital costs of building renovations and ongoing maintenance of building	Building owner pays for all capital costs of building and ongoing maintenance of building  Fraser Health pays lease costs	CSP pays for all capital costs of building renovations and ongoing maintenance of building	Hospice Society (plus Greater Vancouver Housing Corporation at Crossroads Hospice) pay for building costs and ongoing maintenance of building
Equipment and Furnishings	Hospice Society (and other donors) pay for a portion of costs of equipment and furnishings	Hospice Society (and other donors) pay for a portion of costs of equipment and furnishings	CSP pays for capital costs of equipment and furnishings  Hospice Society (and other donors) may pay for a portion of costs of equipment and furnishings	Hospice Society (and other donors) pay for capital costs of equipment and furnishings
Basic Clinical Services and Standards of Care	Fraser Health pays operating costs for basic staff, basic services, pharmacy and medical supplies Fraser Health determines hospice standards, admissions, clinical practice, education, etc. Fraser Health provides Meditech connections and computers for hospice clinical staff			
Management of Staff	Fraser Health manages both nursing and non-nursing staff	Fraser Health manages both nursing and non-nursing staff	CSP manages both nursing and non-nursing staff	Fraser Health manages clinical staff  Hospice Society manages non-clinical staff (housekeeping, laundry, food services)
Additional Services and Comforts	Hospice Society provides volunteers and complementary therapies Hospice Society (or other donors) provide operating costs for television /internet cable, telephones for patients/families Contracted Service provider may provide added-value services and/or comforts			

## 4.6 Models/Approaches of Care: Community-Based End-of-Life Care

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***“Optimal Health” at End of Life: Public Health and Palliative Care and the Compassionate Communities Model*** Dr. Denise Marshall

Currently, in Ontario, inequity remains around Death, Dying, Loss and Bereavement (DDLB). “Healthy living” has become “health services” and “good death” has become “managed death”. We react and support, when there is a problem, not from a place of normalcy. “Psychosocial” has been reduced to “psychological” and “social” in general is missing. DDLB has been reduced to “palliative care services” BUT “a healthcare provider is a poor excuse for a friend”.

In the past, death was understood as:

- Normal, routine and everybody’s business
- Built on community relationships
- Whole person care-ie whole “citizen” care, not just service-base
- End of life care is more than palliative care
- Death and loss are inevitable and universal

*A public health approach to palliative care:*

Every other area of health care has a public health agenda. Palliative and end-of-life care needs one too.

A new concept in palliative care which has emerged over the past decade is that of public health palliative care (also known as Health Promoting Palliative Care (HPPC)). The approach is defined by Dr. Allan Kellehear and based on the World Health Promotion (WHO) Ottawa Charter for Health Promotion. A public health approach to palliative care involves:

- Building healthy public policy
- Creating supportive environments
- Strengthening community action
- Developing personal skills
- Re-orienting health services

A public health approach to palliative care expands our approach to health care to include the community as genuine partners – not simply as targets of our service provision. It moves the approach from direct services, clinical, face-to-face, bedside, acute care, or institutional approaches to community, health promotion and partnership approaches-population based –it is a social movement!

With a public health approach to palliative care, the conceptual and practice emphasis is on:

- Prevention
- Harm reduction
- Health and death education

- Participatory relationships
- Community development
- Service partnerships
- Ecological/settings emphasis
- Sustainability

Within a public health approach to palliative care, the responsibility for palliative care is expanded to ensure that palliative care goes beyond illness and involves populations that are well including schools, workplaces, businesses, unions, places of worship, media, leisure groups, clubs etc. End of life care is restored to the wider public health sphere of policy, practice, and language and involves the state. There is understanding and facilitation that the principle of end of life care is everyone's responsibility.

In order to adopt a public health approach to palliative care, there must be a focus on building social capital and capacity. A community that interacts with itself frequently has a high level of trust, social support and morale. It is interested in its own health and welfare. It fosters interest in matters that affect their family friends, co-workers, neighbours. Building community capital, not occupational skills, requires upfront leadership and facilitation to transition out from Hospice Palliative Care (HPC) and community continuation

Health-promoting palliative care translates hospice ideals of 'whole person care' into broader public health language and practices related to prevention, harm reduction, support, education, and community action. How these ideas express themselves in partnerships between palliative care and the wider community to enhance the quality of life of individuals and communities living with dying, death and loss is described from an Australian example.<sup>103</sup> This entailed:

- Introduction of community development and public education initiatives
- Collaborations with church/template/business
- School/workplace end of life care and grief policies
- Shift towards community sector support and away from palliative care volunteers
- Cultural and media sources of death education
- Mentoring of family carers by family carers.

*Practice Implications of a Public Health Approach:*

- Death education for all (home and away)
- Community development initiatives (home and away)
- Community and service partnerships (learning about equality)
- Empowerment of volunteers (re-orientation and empowerment)
- From bedside to public health (learning to do both)
- Rise of public health workers (making new friends)
- Health promotion starts with our own programs and is NOT health education
- Providing leadership not control
- When DDLB is normalized, Advance Care Planning becomes redundant

An Ecological Approach changes the setting and the conditions without just adding new settings i.e. not a new building, rather hospitals become “hospice friendly hospitals”. Not what we do to others, but with others and is essentially social.

The Compassionate Cities Model is an -end-of life care community application of Healthy Cities (WHO). It is a theory of practice for HPC. Compassion is an ethical imperative for health. Health is a positive concept even in the presence of disease, disability or loss. Compassion is a holistic/ecological idea. Compassion implies a concern for the universality of loss.

*What does success look like?*

- A greater sense of ‘normalization’ around DDLC
- Increase in community involvement, education, and empathy in DDLC (ie care mentors, neighborhood watch, world café, memorial days)
- Government policy changes –as in Australia, Scotland, Ireland, England, India
- Sustainable models and programs

### ***A review of leading practice models in the delivery of palliative care***

The need to build consistent team-based models of care is supported through the HQO End-of-Life Evidentiary Framework. The delivery of health care to people as they near the end of their lives is particularly important, especially with regard to quality of life. Many people need a range of services to help manage symptoms and support physical, emotional, and spiritual needs. Because of the extensive array of care required, consistency of care (that is, having a coordinated team to deliver end-of-life care services) is generally accepted as the optimal care model.<sup>104</sup>

A large number of systematic reviews have examined the effectiveness of specialized palliative homecare compared to usual community care or inpatient care. In general, these reviews of the literature have found compelling trends towards the impact of specialized palliative homecare. Compared to conventional care, there is strong evidence that specialized palliative homecare improves patient satisfaction, moderate evidence that these interventions reduce symptom prevalence, and weaker evidence of the cost benefits of this care.

A recent Ontario literature review examined different palliative care models in terms of their effectiveness and outlined the elements of each – 39 primary studies featuring 29 unique interventions were examined. The beneficial outcomes of the interventions reviewed included significant reductions in: pain, other symptoms including patient and caregiver anxiety, hospital and ED use, and healthcare costs. Significant increases were seen in the proportion of home deaths and in patient/caregiver satisfaction with care received. The four most common elements of the positive interventions were that the team had linkage with acute care, was multidisciplinary, had EOL expertise and training, and provided holistic care to patients, namely practical, physical, and psychosocial/spiritual support. Both pain and symptom management and professional psychosocial support were typical features of many interventions, as was team

linkage with existing community services. Many interventions provided 24/7 on-call for both phone contact and home visits, were linked to the patient's primary care/attending physician, included ongoing assessment of the patient's condition, and involved physicians who did home visits.

A 2014 Ontario study examined eleven community-based specialist palliative care teams in Ontario of varying team size and composition. The study examined whether decedents exposed to the specialist teams, compared to decedents receiving usual end-of-life homecare services, had lower risk of being in hospital or the emergency department in the last two weeks of life, or dying in hospital. The study showed that community-based specialist palliative care teams, despite variation in team composition and geographies, are effective at reducing the risk of being in hospital, having an emergency department visit, or dying in hospital, at the end of life. The core intervention of community-based palliative care—i.e. 24/7 access, educating and preparing patients and families on what to expect next, and being proactive to manage complex symptoms—was effective at reducing acute care utilization despite different team models. The services mattered more than the model. Each team was configured specific to their regional needs. This suggests that every region can have its own unique team, and we should not aim to replicate one model in every community.<sup>105</sup>

EOL care team linkage with acute care and community helps reduce the barriers that service silos impose, which in turn increases inter-agency accountability and helps to facilitate seamless transitions across settings. Providers with EOL expertise and training know what to expect as the patient declines, how to avoid exacerbations at EOL, how to best resolve these crises when they occur, and how to broach sensitive EOL discussions with patients and caregivers. Provider confidence in this knowledge is reassuring to patients and caregivers and serves to reduce the anxiety of these care recipients. As well, EOL care experts are a resource that helps build capacity among generalist providers and family caregivers. Finally, care that is multidisciplinary and holistic is more capable of meeting the diverse and individually unique needs of EOL patients and their families, which often extend well beyond the scope of medical interventions.<sup>106</sup>

Use of technology, integration and coordination, education and use of interdisciplinary teams identified the as key underlying themes that have led to improved resource utilization and service outcomes:

- Leveraging the use of technology has provided health care providers with the ability to provide or delegate care from remote locations or virtual wards thereby, increasing the capacity to treat more patients. The provision of 24/7 or after-hours physician/nurse availability enables on-site care providers to access to specialized clinical consultants and reduces the risk of hospital admissions.
- Coordination of services using a case manager function to screen and assess patients for eligibility align resources required for care delivery have shown to be effective to navigating the healthcare system.

- Interdisciplinary care teams that establish goals and work cohesively to provide comprehensive care directions that ranges from medical care, to nutritional advice, physiotherapy and pharmaceutical advice.
- Investments in palliative care training for physicians (including primary care physicians) and other health care professionals through partnerships with universities, online training and tutorials and education and support for caregivers.

A review of models of care for older individuals with chronic conditions in the United States was undertaken and highlighted the following key successful models where all or most of them lead to improved quality of care, improved quality of life, increase in functional autonomy and lower use of health services.<sup>107</sup>

- Interdisciplinary primary care teams consisting of a primary care physician and one or more other healthcare professional (i.e. a nurses, nurse practitioners, social workers, rehabilitation therapists)
- Care or case management to assess patients, communicate with health care providers and assist patients to navigate the healthcare system. Case management has been associated with better satisfaction with care, quality of care, quality of life and survival.
- Disease management programs that provide patients with education and information about their chronic conditions in writing or telephone and has resulted in fewer hospital admissions for patients with specific chronic conditions.
- Preventative home visits by physicians/nurses or other health professionals has reduced mortality and LTC home admissions
- Outpatient comprehensive geriatric assessment and geriatric evaluation and management identify all of a person's health conditions, develop treatment plans for those conditions and implement treatment plans have led to improved quality of care.
- Pharmaceutical care and advice provided to patients either directly or through interdisciplinary teams improve adherence to medication, disease specific outcomes and reduced use of hospital services.
- Chronic Disease Self-Management provides structured and time interventions to enable the patient to actively engage in managing their chronic conditions resulting in better quality of life and functional autonomy and in some cases, greater efficiency in the use and cost of health services.
- Education and support programs to provide caregivers with education, training, coping strategies, counselling and emotional support provide a significant benefit to the patient's quality of life.
- Prevention and management of delirium through routine screening, using evidence based guidelines to address risk factors for older patients.
- Effective transitional care to enable smoother, safer and efficient transition between health services.
- Hospital at home programs that enable specific acute conditions to be treated at home by a team of health professionals including physicians and nurses have resulted in improved quality of life and a reduction in hospital utilization and healthcare costs.

## ***Evidence of Integrated Services and Programs***

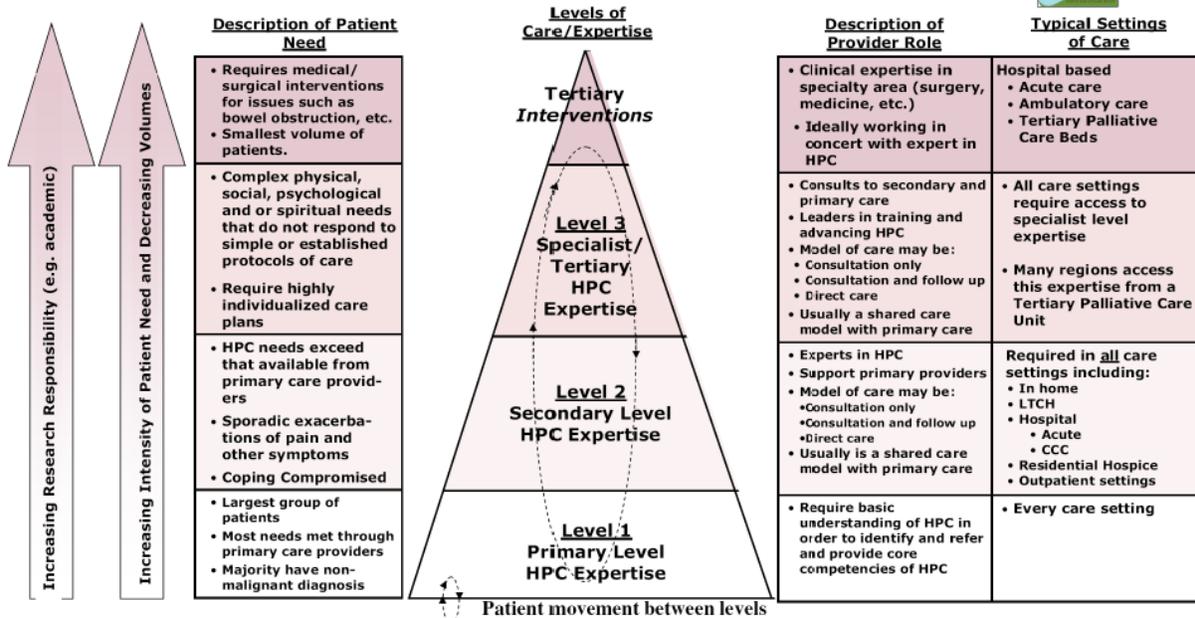
### ***Capacity-Building Model for Rural and Aboriginal Communities***

The purpose of this research was to validate a conceptual model for developing palliative care in rural communities. This model articulates how local rural healthcare providers develop palliative care services according to four sequential phases. The data validated the conceptual model as the model was able to theoretically predict and explain the experiences of the 7 rural communities that participated in the study. The model was confirmed as being a useful theoretical tool for conceptualizing the development of rural palliative care that is applicable in diverse rural communities.<sup>108</sup>

### ***Home-Based Care in a Shared Care Model—Ontario<sup>109</sup>***

Shared care is established when interdisciplinary specialist palliative care teams (usually comprised of a palliative care physician, an advanced practice nurse, a psychosocial spiritual advisor, a bereavement counselor, a case manager and an administrator) form partnerships with primary care providers (usually frontline family physicians and home care nurses) to support the complex needs of terminally-ill patients and their family members in the home setting. Palliative care teams overcome gaps in the health care system, such as: lack of palliative care specialists; poor coordination and integration of care, and; a health care workforce with insufficient training in palliative care. This type of service delivery model is common in medical specialties such as mental health and obstetrics, and various forms of palliative shared care have been implemented in other countries such as the US, Australia, UK, Italy and Spain, where it has been shown to be cost-effective. A conceptual model for delivering palliative care in Erie St. Clair LHIN, providing an example of the current medical, cancer-focused model frequently observed in Ontario can be seen in Table 1.

Providing Hospice Palliative Care (HPC) in Erie St. Clair –Conceptual Model



Model developed for Erie St. Clair End of Life Care Network (ESC EOLCN), by Beth Lambie—Director ESC EOLCN (Sept.2008, revised Dec. 2008, Jan. 2009)

This model incorporates concepts, design and content from: 1) Palliative care Australia—A Guide to Palliative Care Service Development (2005) pg. 14 & 15; 2) Unpublished work by Dr. D. Dudgeon (1992), 3) Chronic Disease Management Framework –ESC LHIN—Ralph Garter (2008), 4) CHPCA Model (2002) pg. 56, 5) Cancer Care Ontario—Regional Models of Care-March 2009 (relating to research responsibility). Note—Regional variations may result in: level 3 being subdivided to create a 4th level (quaternary level) or level 2 and 3 being merged to create a single level of specialist care.

Table 1

There are few palliative care teams working in a shared care model in Canada; this provided the impetus to investigate the process of how this integrated approach is developed and sustained within the context of specific populations and geographies. A longitudinal case study in a Local Health Integration Network (LHIN) area in Southern Ontario, comprised of urban and rural communities, was conducted in order to evaluate barriers and facilitators in using a shared care model from the perspective of team members, key-informants and stakeholders. The evaluation of barriers and facilitators informed recommendations to guide the sustainability of palliative care teams working in a shared care model:

**Community:**

- Teams must continue to engage primary care providers through capacity building initiatives.
- Teams should be housed in a therapeutic environment such as a residential hospice or community hospital in order to assist with patient transitions.
- The type of shared care model pursued by the team should be informed by the community and primary care context (e.g., via needs assessment or a community meeting).
- Teams should refrain from a total “takeover” model as it may decrease the capacity of primary care providers, and become unmanageable.

**LHIN:**

- The LHIN, Hospice Palliative Care Network and CCAC must align themselves and work in collaboration to champion the service delivery model and to advocate for team resources.
- It is advised that the CCAC work with nursing agencies to negotiate that nurses attend community rounds to enhance their capacity in palliative care.
- The LHIN must play a role in integrating, fostering, and formalizing partnerships between community stakeholders and teams.
- The LHIN in collaboration with the Hospice Palliative Care Network should assist teams in demonstrating their relevance by building on existing evidence of cost effectiveness.

**Province:**

- The province needs to allocate dedicated funding to non-physician health care providers on palliative care teams.
- The province must acknowledge current disparities in the provision of home-based palliative care and the added value of teams.
- A provincial strategy endorsing palliative care teams and the shared care model is a step in the right direction.
- Incentives for family physician home visits should be considered as a means of improving buy-in for shared care.

***e-shift – South West CCAC, Ontario***

The e-Shift model places PSWs at the bedside, who are linked to a delegating nurse in a different location using real time technology. The project stemmed from efforts to identify ways to increase capacity by leveraging specialty clinical resources virtually by providing hands on care at the bedside. Specially trained PSWs report signs and symptoms using a smart phone application that is linked to a secure portal monitored by a nurse. The nurse delegates the appropriate intervention in real time. The nurse is able to monitor up to four PSWs and the clinical data they input, at the same time. The portal is also accessible by other individuals on the care team (i.e. physicians). “The e-Shift model maximizes the scope of practice of care team members to provide the right service by the right person in the right place at the right time. While the clinical monitoring for these clients is critical, the majority of direct care provided by the nurse at the bedside in the traditional model is actually task based, comfort measures that could be provided by non-regulated providers.”<sup>110</sup>

By leveraging a specialty nurse’s clinical expertise across multiple clients regardless of their location, HR pressures are offset, the client’s quality of life is improved and hospital and emergency department resources are use is avoided.

Teaching, observing and delegating appropriate tasks by a nurse to a PSW is a common practice and within all clinical standards all guidelines. This is generally done face to face and the PSW carries out the task in the absence of the delegating nurse. A literature review found no examples nationally or internationally, where delegation was conducted and/or continuously monitored electronically.

A number of outcomes of the model were described by healthcare providers and decision-makers including: attending to the client's wishes to die at home, relieving caregiver burden, perception that emergency room admissions (and use of ambulance services) were reduced; hospitalizations were reduced and improved recruitment and retention of healthcare providers<sup>111</sup>

### ***Care Team Coordination in a Rural Setting – Prince Edward Hospital @ Home Pilot***

The Prince Edward Family Health Team (PEFHT) and CCAC have created a 2 year Prince Edward Hospital @ Home (H@H) pilot in attempts to reduce hospital admission and readmission rates and reduce the average length of stay. Creation of a Hospital at Home (H@H) model following research (Queens University) including a review of literature on well-established “Virtual Ward” and “Hospital in the Home” initiatives around the world and discussions with key informants. Eligible patients must live in a home environment suitable for their care and home visits by others. Patients will be referred for admission to the H@H program by a physician.

Patients are cared for by a Care Team consisting of the Most Responsible Physician, Team Leader, CCAC Care Coordinator, personal support workers, nurses, nurse practitioner, pharmacists and social worker. Additional Care Team members may also include a physiotherapist, occupational therapist, nutritionist, wound care nurses, COPD nurse, community health provider or other appropriate health care professional. The Care Team works together to establish goals and in discharge planning. Information is exchanged between the Team members on a daily basis. The CCAC Care Coordinator works closely with the Team Leader to ensure that the all necessary patient care is provided by the right Care Team member and to coordinate services being provided by the CCAC.

The MRP will make daily comprehensive visits to the patient's home in person or through 'virtual home visits' in which case, a clinician will visit the patient's home and examine the patient and perform any necessary interventions under the supervision of the physician via secure video linkage.

The H@H Pilot can manage a maximum of 12 patients at a time, living within a 12 km radius of the Prince Edward FHT, with admission restricted to frail elderly patients (including those with dementia) and patients requiring palliative care, who would otherwise require admission to hospital.

### ***Integration Across Settings – Edmonton, Alberta***

The Edmonton integrated palliative care model integrates care across 5 settings: the home, 5 hospices, a hospital based tertiary palliative care unit, acute care hospitals and the regional cancer institute. The model has implemented a fee code to incent family physicians to participate in the 24 hour on-call coverage program as well as act as attending physician to patients in hospices. The program can be accessed a single number. All requests for consults

are screened by a triage physician who coordinates the appropriate team members to the consult at the site of care (home, LTC home, community hospitals).

### ***Winnipeg Regional Health Authority Community Model of Palliative Care***

WRHA Palliative Care Program is an integrated program across the spectrum of care settings (home, LTC, acute care). See link below:

<http://www.gov.mb.ca/health/mpan/pdf/palliative.pdf>

### ***Palliative Services for Aboriginal Communities – British Columbia***

The article presents findings examining palliative care services and provisions in the rural interior of British Columbia (BC). The analysis was based on findings in three Aboriginal communities that are lightly populated but widely dispersed through interviews with individuals with roles in palliative care (nurses, doctors, pastors, hospice volunteers, family caregivers) Four necessary elements were identified to enhance the provision of palliative care for Aboriginal clients:

1. Allocating resources to establish strategies such as culturally specific practices (i.e. smudging) that will facilitate experiencing a good death.
2. Providing culturally safe care that supports people in claiming and embracing their Aboriginal identity at end-of –life.
3. Giving care in spaces that do not re-institutionalize Aboriginal people
4. Offering training to formal and informal service providers regarding cultural practices in death and dying.

### ***Bridging Programs – United States***

Enabling earlier home access to hospice care services Bridging Programs (United States) Bridging programs enable patients to receive hospice services earlier than can be provided under the Medicare Hospice Benefit (MHB) in the US (see Sections 5.2 and 5.3). These programs are based on the concept that end-of-life care can be enhanced by better integration of palliative care throughout the continuum of care (ASCO, 2008). Limited research evaluating bridging programs was identified. However, results suggested there was a slower decline in the quality of life among patients provided with earlier access to hospice care compared with those receiving hospice care later, although no difference was noted in symptom control. A preliminary comparative cost analysis also revealed a 27% reduction of cost in the intervention group, representing an extrapolated cost savings of \$2,540 per patient (less chemotherapy, diagnostic, professional and hospital services) (Finn, 2002).

### ***Open Access Models - United States***

An open access hospice provides treatments that palliate symptoms and enhance quality of life, even if the treatments are considered to be disease directed rather than purely palliative. This model was developed to help individuals avoid the “all-or-none” decision between continued treatment provided by a hospital and end-of-life, palliative care provided by a hospice (ASCO, 2008). A 2007 randomized controlled trial found that patients receiving more extensive in-home palliative care services organized on an open access model (e.g., allowing for access to treatments that may be considered “curative”) were three times as likely to report high levels of satisfaction as those in the control group (receiving standard in-home palliative care). Moreover, patients in the intervention group also had fewer 911 calls and fewer life-sustaining interventions conducted in the emergency department or intensive care unit (Brumley et al. 2007).

### ***The Catalonia World Health Organization Demonstration Project for Palliative Care Implementation***

Twenty years ago, the World Health Organization (WHO), in collaboration with the Catalan Department of Health and the Catalan Institute of Oncology, began a demonstration project (WHO Demonstration Project) in palliative care (PC) with the aim of implementing specialist PC services, generating experience in this field, identifying areas for improvement, and introducing educative procedures (clinical and nonclinical). Over the past 20 years, 237 PC clinical services (72 home care support teams, 49 hospital support teams, 60 units with 742 dedicated beds, 50 outpatient clinics, and six psychosocial support teams among others) and four nonclinical services (education, research, WHO Collaborating Center, and planning) have been implemented. The overall yearly costs are around €52,568,000, with an overall savings of €69,300,000 (€2275 per patient, net savings of €16,732,000).

#### **Cost and Savings of PC Services**

<b>Type of Service</b>	<b>Calculation</b>	<b>Subtotal/Type</b>	<b>Estimated Savings in Euros</b>
Home Care Support Teams	229,000 x 72 services	16,488,000 (31%)	Total savings: 3000/patient x 23,100=69,300,000  Net savings: 16, 732,000/year
Hospital Support Team	279,000 x 49 services	13,671,000 (26%)	
Palliative Care Unit	96 x 209,000 stays	20,064,000 (38%)	
Outpatient Clinic	155 x 9000 processes	1,395,000 (3%)	
Psychosocial Support Team	190,000 x 5 services	950,000 (2%)	
<b>Total</b>		<b>Total costs: 52,568,000/year</b>	

### ***Western Australia***

The Silver Chain Group in Western Australia has reported 60% of death at home compared to the national average of 25% to 30% with initiation of their model. Most people who die at home have no hospital admissions during care<sup>112</sup>. This model:

- Provides services for patients with life limiting illness, regardless of diagnosis
- Addresses the palliative care needs of patients and their families during their illness trajectory
- Delivers care in any setting-hospital, palliative care unit, residential care or home
- Identify partnerships between specialist palliative care services and primary care providers

## 4.8 Communication at End of Life

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### *End-of-Life Health Care in Ontario: An Evidentiary Framework (Dec 2014)*

This report provides evidence to support the need for a broader public discussion about the normalization and de-medicalization of death and dying. Fifty-five percent of Canadian adults have never had a discussion about their end-of-life care preferences with either a family member, friend, doctor, lawyer, or financial advisor, states an online national survey carried out by Harris/Decima in 2013.vii Most attributed initial reluctance to discussing end-of-life care to not wanting to upset family members (76 percent) and not knowing enough about their options (70 percent).<sup>113</sup>

Understanding the impact of CPR on patients at the end-of-life is important, as some may prefer to not undergo this intervention if they are provided with accurate information on their quality of life after receiving it. A Canadian study showed that seriously ill hospitalized patients have poor knowledge about CPR, low rates of survival, and, quite often, very poor perceived quality of life in the event of successful resuscitation.vi Proactive discussions about a patient's goals of care should inform health interventions at the end-of-life.

### *National Dialogue on End-of-Life Care: Canadian Medical Association*

On June 10, 2014 the Canadian Medical Association (CMA) issued a final report from its tour between February and late May 2014. The national dialogue focused on three main issues: advance care directives, palliative care, and physician-assisted dying. Beyond seeking input from Canadians on their views about the status of end-of-life care in Canada, the National Dialogue also sought to establish a common set of definitions and terminology to inform and frame discussion on end-of-life care issues. The Dialogue also included an educational element that described the current legal and legislative situation in Canada and abroad.

The report makes a number of conclusions based on the consultation including:

- All Canadians should discuss end-of-life wishes with their families or other loved ones.

- All Canadians should prepare advance care directives that are appropriate and binding for the jurisdiction in which they live.
- A national palliative care strategy is needed.
- All Canadians should have access to appropriate palliative care services.
- Medical students, residents and practicing physicians need more education and training about palliative care approaches and greater knowledge about advance care directives.
- Should Canada change laws to allow physician-assisted dying, strict protocols and safeguards are required to protect vulnerable individuals and populations.

The final report can be accessed using the following link: <http://www.cma.ca/advocacy/end-of-life-care>

***Improving End-of-Life Communication and Decision-Making in Ontario, November 30, 2013***  
***Improving Access to Palliative Care in Ontario, November 16, 2013***

Over two different sessions, citizens from throughout the province of Ontario were brought together to share their views about and experiences with improving end-of-life communication and decision-making, including consideration of:

1. Improving public awareness about palliative and end-of-life care

**Option 1 – Improving public awareness about palliative care**

**Summary of what is known about social marketing campaigns**

- Social marketing campaigns can be effective to:
  - encourage voluntary health behaviour change;(42;43) and
  - bring about changes in the environment in which we live and in public policies.(43)
- Shorter social marketing campaigns generally achieved larger impacts.(42)
- Online social marketing campaigns have similar effects to sophisticated print campaigns, but have the advantages of reaching more people and lower costs.(42)
- No systematic review identified negative consequences of social marketing campaigns.

2. Engaging citizens in a dialogue to encourage open discussions about end-of-life care;

### **Option 2 – Engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care**

#### **Summary of what is known about public dialogues**

- Methods allowing informed discussion among citizens (in contrast with more traditional methods like surveys and focus groups) can:
  - enhance their awareness and understanding about an issue;(45-47) and
  - increase their competence for future public engagement activities.(45-47)
- There is limited evidence about the effectiveness of different types of methods to engage the public in developing healthcare policies,(45;49;50) in defining priorities and in allocating resources.(51)
- No systematic review identified negative consequences of public engagement.

### 3. Providing citizens with tools and information to engage in advance care planning

### **Option 3 – Providing citizens with the tools and information they need to engage in advance care planning**

#### **Summary of what is known about strategies to inform and educate the public**

- Mass media campaigns
  - An old but high-quality review that examined the effects of using mass media on the utilization of health services found benefits for planned mass media campaigns and unplanned mass media coverage on the utilization of health services.(52)
  - However, the authors found limited evidence about the characteristics of successful mass media campaigns, and notably about how messages should be framed.(52)
- Mailing information to citizens
  - A recent overview of systematic reviews examining the effectiveness of different types of interventions to increase the completion rate of legal documents that allow people to express their wishes for end-of-life care found that:
    - the most effective way to increase the completion rates was combining information material (for example, mailing pamphlets and forms about the Power of Attorney for Personal Care) and repeated conversations with healthcare providers during clinical visits;(53) and
    - the use of passive information material alone does not significantly increase the completion rates.(53)
- No systematic review identified negative consequences of public information and education.

### 4. Supporting patients and families to navigate the system

### **Option 2 – Supporting patients and families to navigate the system**

#### **Summary of what is known about health system navigators**

- Health system navigators appear promising to provide integrated and coordinated care, using a variety of interventions such as care plans and treatment goals.(46)
- Health system navigators could improve:
  - satisfaction for both patients and healthcare providers;(46)
  - the patients' quality-of-life and functionality;(46)
  - participation in cancer screening;(47) and
  - adherence to follow-up care after the detection of an abnormality.(47)
- No systematic review identified negative consequences of health system navigators.

## 4.9 Compendium of Research

This appendix outlines emerging or planned research that is relevant to the themes and issues outlined in the Strengthening Ontario's End-of-Life Continuum report. Further consideration of new research and data as it emerges will strengthen implementation of these directions as well as the action commitments and priorities outlined in the Declaration of Partnership and Commitment to Action.

### Part 1: Emerging research environment (Initiatives currently underway as of Fall 2014)

<i>Project Name</i>	<i>Research Lead</i>	<i>Status</i>	<i>Final Report</i>	<i>Topic in Brief</i>
<b>Client Characteristics, Service Utilization &amp; Costs</b>				
<b>CCO Asset Map</b>	CCO		TBD - 2015	Analysis of palliative care-related services including residential and non-residential hospice services, palliative care units, consultation teams in hospitals, consultation teams in the community, and outpatient palliative care clinics. The data being collected will include service utilization (i.e. number of referrals and admissions, LOS, wait times, etc.) as well as staffing and staffing ratios etc.
<b>ICES and HSPRN End of Life Research</b>	ICES/HSPRN	underway	3 year project (2013-2016)	HSPRN (Peter Tanuseputro) is leading a 3 year research project to study health care use and cost of dying in Ontario
<b>Funder: MOHLTC grant</b>				
<b>HSPRN Applied Health Research Question (Data and Performance)</b>	ICES/HSPRN	AHRQ#2: underway	AHRQ #1: received	HSPRN has completed one AHRQ, and continuing a follow-up AHRQ with the Central East LHIN, on behalf of the Declaration of Partnership subcommittee on Data and Performance. These AHRQ's have identified patients receiving palliative and end of life care through the use of current health administrative databases. They describe the care setting, timing, intensity and continuity of palliative care provided in Ontario in the last year of life. They will
<b>Sponsor: Central East LHIN (Lauren Chitra)</b>				

				also establish a breakdown of health care use and cost across the continuum of care sectors for those receiving and not receiving palliative care, including an examination of Long-Term Care, Complex Continuing Care, Rehabilitation and Home Care. To date, this study has focused on a retrospectively defined decedent cohort. The study has not prospectively examined frail or complex cohorts who, although they may not be formally recognized in the system as palliative or EOL, may meet one or more of the criteria in the UK Gold Standards Definition of end-of-life.
<b>Frail Senior Analysis and Chartbook</b>  <b>Funder: MOHLTC grant</b>	ICES	Initiated in 2010	Final report Fall 2014	ICES (Susan Bronskill) is leading a 3 year research study on Public Reporting on Seniors' Health and Service Expansion Impact. As part of this work, ICES is producing a Chartbook of Older Populations that focuses on a number of older adult cohorts, including a number of frail/complex older adult cohorts and palliative care cohorts
<b>Predictors of Place of Death Across the Home-Based Palliative Care Trajectory</b>	Denise Guerriere	undergoing peer review	TBD	Assessment of the economic, demographic, clinical and psychosocial determinants that account for home deaths in patients receiving home-based palliative care.
<b>Quality of Care</b>				
<b>First Nations Palliative Care</b>  <b>Funder: CIHR grant</b>	Dr. Mary Lou Kelley Lakehead University	underway	5 year project (2010-2015)	Overview of end of life care in First Nations communities and ways to improve (May 13, 2014). The goal of the research is to improve end-of-life care in four First Nations communities through developing palliative care programs and creating a culturally appropriate theory of change to guide palliative care program and policy development nationally. 4 partnering First Nations communities (3 in Ontario and 1 in Manitoba)
<b>Improving General Practice Advance Care Planning. The I-GAP</b>	Howard/ Heyland McMaster	underway	HSRF Capacity Award—	Work is underway to develop, adapt, and evaluate tools and resources to be used by patients and health care providers to facilitate Advance Care Planning.

<b>Study</b>	University		three year funding beginning 2014-15	
<b>Funder: MOHLTC grant</b>				
<b>Quality Palliative Care in Long Term Care Toolkit</b>	Dr. Mary Lou Kelley	Presented	January 20, 2014 (Ongoing)	The major finding of this research was the creation of a palliative care program that considers the unique setting and context of care delivery in long term care and consists of a program framework and toolkit for implementation of the framework. The Quality Palliative Care in Long Term Care Framework includes three core components: a philosophy of palliative care, a program description and organizational policy, and a process for organizational change. These core components are supported by 40 tools, modules, in-services, and innovations for direct care, education, and community partnerships which were also created by the Alliance.
<b>Re-Thinking Palliative Care in Communities</b>	Dr. Hsien Seow, McMaster	Released		Summary of research informing how to build high quality palliative care teams
<b>The INTEGRATE Project</b>	Jose Pereira/CCO	Jan 2014 kick off	Interim evaluation report Sept 2015 -final report Mar 2017	Project Goal-Enable identification and management of patients to benefit from a palliative care approach early and across settings through <ul style="list-style-type: none"> <li>• Adapting and implementing provider education</li> <li>• Implementing Integrated Care Models</li> </ul>
<b>Funder: CPAC grant</b>				
<b>Hospital@ Home pilot for rural Ontario</b>	Jyoti Kotecha/ Queen's University		March 2015	Pilot to demonstrate that for frail elderly and palliative care patients in a rural setting hospital admissions/ER visits can be avoided and readmissions reduced through admission to the pilot team. The aim is to divert appropriate patients requiring inpatient care to a program that wraps the necessary care around the patient in their home.
<b>Hospice Prince Edward Pilot</b>	Donna Logan Nancy Parks	Ongoing, internal	Fall 2014	This is a pilot to explore the viability of small residential hospices in rural communities where the demand for beds is low (3 beds). This

		evaluation underway		small hospice has unique challenges and has existed without 24/7 nursing care. The pilot is currently undergoing internal audit and assessment.
<b>eShift</b>	Dr. Sandra Regan, Dr. Lorie Donelle, Ms. Gwen Vanderheyden Western University	Initial evaluation 2012	Ongoing spread	The purpose of this pilot study was to investigate how a Health Information Technology enhanced model of care delivery can enhance palliative homecare services.

## PART 2: Planned new research

To address important information gaps, the Working Group and MOHLTC have initiated the following new research projects.

Together, these projects will improve our knowledge of the needs, characteristics and utilization patterns of patients approaching end of life, regardless of care setting; help us prospectively identify groups of patients approaching end of life at a population and community level; and enable improvement of the quality of care delivery through a proposed audit and feedback intervention by building awareness of shared group outcomes at multiple levels and highlighting actionable areas for improvement. (see appendix for research abstracts)

<b>Project Name</b>	<b>Research Lead</b>	<b>Status</b>	<b>Final Report</b>	<b>Topic in Brief</b>
<b>TBD</b>	Dr. Anik Giguère, Université Laval	Contract Awarded	December 2015 and an interim report with a summary of results to-date in early June 2015	This project consists of designing and implementing a benchmark study (environmental scan) that systematically examines current care of the seriously ill, frail elderly nearing end of life. The study will use a mixed methodology, and most quantitative data will come from existing national and provincial patient health databases such as the Canadian Institute for Health Information (CIHI), the Ontario Institute for Clinical Evaluative Sciences (ICES) and similar databases in other Canadian provinces.
<b>Profiles of End of Life</b>	Dr. John	In progress	Mar 2015	Home and Community Research and Knowledge Exchange Chair

<b>Patients using InterRAI Data</b>	Hirdes and Leslie Eckles	– part of Home Care Research and Knowledge Exchange Chair		(John Hirdes) has been engaged to provide an analysis of how different identified cohorts based on interRAI data compare in terms of their profile, care needs, service and utilization patterns, outcomes and the comparative costs of care delivery across different care settings? How do the possible end of life cohorts which are easily detected within interRAI datasets compare to our overall assumptions about end-of-life patients within the general population?
<b>Prospective Identification of end-of-life cohorts within existing health system data sets</b>	ICES (Susan Bronskill) and HSPRN (Peter Tanuseputro)	Part 1 approved as an ICES AHRQ project. Data analysis will commence in spring 2015	Dec 2015	This project will leverage ICES and HSPRN data sets to provide a fuller understanding of the comparative profiles, the costs and utilization patterns of cohort of patients who may be frail, complex, and who have high risk of mortality within a one to two year timeframe. This analysis will examine what are the best methods to prospectively identify cohorts of frail and complex patients with a high risk of mortality through the use of current health administrative databases? The identification of these cohorts would allow for targeting of future interventions to improve care and reduce costs for the frail.
<b>Home and Community Audit and Feedback Intervention (including end of life populations)</b>	Dr. Noah Ivers	Approved as a Western, HSPRN, McMaster AHRQ project	Summer 2016	This project will build awareness of the profiles of groups of home and community patients with similar needs and risk severity (including an end of life group specifically) and measure how aggregate (or shared) health status, utilization, costs and experience outcomes for defined population subgroups differ a) across regions and, b) over time. Use of audit and feedback systems is an evidence-based quality improvement approach that has significant potential to improve the quality of care coordination in the home and community care sector.

## 4.10 Community Residential Hospice Standards 2012 (HPCO)

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### Section A: Clinical Care

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#### **Standard A1. Model of Care**

##### **Standard statement A1.1**

Each Community Residential Hospice has a model of care which is collaborative in nature and provides palliative care using a holistic approach through an interprofessional team\* that has expertise in palliative care.

##### **Criteria**

- The Community Residential Hospice will address the psycho-social, physical, practical and spiritual needs of the resident, be adult or child, and their significant others with the aim to improve quality of life.
- The Community Residential Hospice will develop a treatment plan based on the assessment of those needs.
- The Community Residential Hospice will implement the plan using interprofessional teams of professionals with expertise in hospice palliative care aiming to deliver symptom control and improve quality of life.
- The Community Residential Hospice will utilize the assistance of volunteers according to each individual hospices needs.

##### **The Interprofessional Team**

Professional Staff includes:

- Regulated Healthcare Professionals: Registered Nurses, Registered Practical Nurses, Nurse Practitioner, Physicians, Pharmacists, Physiotherapists, Social Workers, Social Services Workers.
- Non-regulated Healthcare Professionals: Personal Support Workers, Paramedics, Music Therapists, Spiritual Care therapists, medical students, nursing students, other healthcare students.

Other members of the team:

- Significant others of the person: Family, friends.
- Resident: The person receiving care
- Volunteers: members of the public who have undergone specific training, of at least 30 hours, in hospice palliative care.

#### **Standard A2. Access to Hospice**

##### **Standard statement A2.1**

Each Community Residential Hospice has eligibility criteria\* and a clear referral process.

## **Criteria**

Persons eligible for service include:

- Those living with a life threatening progressive or terminal illness with a pre-determined prognosis and life expectancy
- Have an understanding that resuscitation and other life sustaining interventions are not offered as they are deemed to be of no benefit to the person in the end of life phase
- It is understood that in pediatric hospices the pro's and con's of resuscitation and other life sustaining interventions and their impact on end of life care will be discussed on an individual case by case basis
- Those living within the geographical boundaries of the hospice as determined by each hospice
- Receiving services from CCAC
- Meet eligibility criteria for individual hospice

\*Persons who do not meet the eligibility criteria are referred to appropriate service(s)

## **Standard A3. Assessment**

### **Standard statement A3.1**

The Community Residential Hospice has comprehensive and ongoing person-centered assessments which are performed by professional staff prior to admission and ongoing throughout residential care.

## **Criteria**

- The Community Residential Hospice has professional staff dedicated to performing assessment prior to admission and ongoing throughout the person's residential care or program participation in order to identify goals of care and the development of a treatment/care plan.
- Assessment is performed by professional staff using a variety of evidence based tools and techniques to assess all domains of issues/care including:
  - Physical
  - Psychosocial
  - Social
  - Spiritual
  - Practical
  - End of life care
  - Grief bereavement
- All assessments will be documented according to relevant regulatory standards where applicable.

## **Standard A4. Information Sharing**

### **Standard statement A4.1**

Community Residential Hospices have an ethical and legal responsibility to maintain the confidentiality and privacy of health information of any persons in their care.

#### **Criteria**

- Personal health information can be shared among health care team members to facilitate seamless and effective care (Personal Information Protection Act (PHIPA), 2004). The health care team consists of all those who are involved in the care of the person regardless of if they work for the same organization or not.
- Personal health information must be kept confidential and secure.
- Personal health information consists of :
  - Physical or mental health, including family health history;
  - Care previously provided (including the identification of people providing care);
  - Payments or eligibility for health care;
  - Donation of organs and tissue;
  - A person's health number;
  - The name of the person's substitute decision maker\* (SDM).
- According to PHIPA Community Residential Hospices are considered Health Information Custodians (HICs) i.e. an organization that provides care within the health care continuum.
- Staff and volunteers who receive health care information are agents of HICs and must comply with all legislation.
- Community Residential Hospices shall have policies in place relating to confidentiality
- All staff and volunteers must receive education on privacy and confidentiality and agree to sign a confidentiality agreement with the Hospice.
- Personal health information should only be collected as needed to address care needs of that person and used accordingly.
- All residents are entitled to receive a copy of their personal health information and must expressly consent to the collection, use and disclosure of their health information.
- The Community Residential Hospice strives to have access to assistive services when there is a barrier to communication (as identified by either the resident or the professional staff) in order to provide information which is understood by the resident and their significant others.

### **Standard A5. Care Planning**

#### **Standard statement A5.1**

The Community Residential Hospice has a treatment plan of care for each resident in alignment with the *Health Care Consent Act 1996* (subsection p (Treatment)).

#### **Criteria**

- The Community Residential Hospice has a plan of care or treatment plan for each resident based on their health care needs, diagnosis, prognosis and wishes.

- The Health Care Consent Act 1996 defines “treatment” as a procedure or set of procedures that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment or group of associated treatments, but does not include:
  - an examination or assessment conducted in accordance with this Act, the Adult Protection Act R.S.P.E.I. 1988, Cap. A-5, the Mental Health Act, the Public Health Act R.S.P.E.I. 1988, Cap. P-30, the Public Trustee Act R.S.P.E.I. 1988, Cap. P-32.2 or any Act respecting capacity\* or guardianship of the person,
  - the assessment or examination of a person to determine the general nature of the person's condition,
  - the taking of a person's health history,
  - the communication of an assessment or diagnosis,
  - the admission of a person to a hospital or other facility except as provided in section 15,
  - a personal assistance service,
  - a treatment that in the circumstances poses little or no risk of harm to the person,
  - counselling that is primarily in the nature of advice, education or motivation, anything prescribed by the regulations as not constituting treatment.

1996,c.10,s.1; 2005,c.40,s.5; 2008,c.8,s.5(2); 2010,c.31,s.3
- The treatment plan is monitored and evaluated regularly.

### **Standard statement A5.2**

Each resident receives the necessary information to make informed decisions about treatment options, goals of care and expected outcomes.

#### **Criteria**

- The Community Residential Hospice has processes in place to determine capacity\* of the resident.
- The Community Residential Hospice ensures professional staff and volunteers understand the Substitute Decision Act (1992) and discuss with the resident their wishes should they become incapable.
- Professional staff deliver information about treatment options based on their expected outcomes, risks and benefits, alternates to treatments (including no treatment) and document the conversation according to regulatory standards.
- Informed consent for treatment is obtained from the capable resident or SDM if the person is not capable.

### **Standard A6. Care Delivery**

#### **Standard statement A6.1**

The Community Residential Hospice provides care delivery from professional staff 24 hours a day, 7 days a week to meet the residents' needs in accordance with each resident's plan of care/treatment plan.

### Criteria

- Individualized care is delivered by an interprofessional team\* consisting of at least
- Registered Nurses (RN's), Personal Support Workers (PSW's), Palliative Care Physician.
- The Community Residential Hospice has a Registered Nurse on site 24 hours a day 7 days a week.
- The Community Residential Hospice has physician coverage either from a palliative care physician or the residents' family physician 24 hours per day, 7 days per week.
- Community Residential Hospice may have access to nurse practitioner support.
- The Community Residential Hospice has access to medical equipment.
- Medical equipment can include but is not exhaustive of:
  - Suction machine;
  - Oxygen;
  - Therapeutic scientific surfaces for maintenance of skin integrity;
  - Moving and handling equipment such as mechanical lift and aids;
  - Ambulatory infusion devices;
  - Dressings;
  - Syringes and sharps disposal;
  - Other equipment as required
- Care is delivered in a way to optimize infection control best practices.

### Standard statement A6.2

The Community Residential Hospice strikes partnerships with external and internal health care providers to facilitate seamless care and meet the holistic needs of the resident as well as incorporating the needs of the families.

### Criteria

- The Community Residential Hospice strives to eliminate fragmentation and duplication through the use of common tools, processes, resources and partnerships.
- The Community Residential Hospice refers to external care providers when necessary to meet the needs of the resident e.g. chaplain, spiritual care consultant, respiratory therapist.

## Section B – Governance

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### Standard B1. Board of Directors

#### Standard statement B1.1

The Community Residential Hospice has a Board of Directors operating under a governance philosophy that is described in writing.

### Criteria

- The Board ensures the culture of the Hospice aligns with the mission, vision and values of the organization
- The Board ensures the organization complies with its own governing documents and all applicable federal, provincial and municipal laws and regulations.
- The Board has developed Board manual/policies which govern their practice, identifies their responsibilities/accountabilities and outlines the specific roles of officers of the Board.
- The Board ensures a strategic plan is in place.
- The Board holds sufficient number of meetings annually to fulfill its duties, including an Annual General Meeting.
- The Board is accountable for the recruitment and orientation of the most senior staff person in the Hospice. The process is fair and transparent.
- The Board is accountable for ensuring the most senior staff person has a comprehensive job description, annual performance objectives and review. The compensation of the most senior person is approved by the Board.
- The Board reviews the insurance policies of the Hospice annually.
- The Board has a Board-approved code of ethics/conduct with which all of its directors, staff and volunteers are familiar with and to which they adhere.
- There is a Board-approved conflict of interest policy that applies to Board, staff, and volunteers and provides disclosure, review and decision on actual or perceived conflicts of interest.
- The Board has a process in place for annual performance review of the Board and its directors, chair, committee chairs and other officers of the Board.
- The Board has an open and transparent process for recruitment of the directors who must be at arm's length to each other.
- No member of the Board is entitled to receive, either directly or indirectly, any salary, wages, fees, commissions or other amount for services rendered to the Community Residential Hospice in their capacity as a director.
- Each new Board member is given an orientation to both the operations of governance of the organization.

## **Standard B2. Financial**

### **Standard statement B2.1**

The fiduciary accountability of the Board of Directors of the Community Residential Hospice is clear and understood.

### **Criteria**

The Board is accountable for the fiduciary sustainability of the Community Residential Hospice.

- The Hospice's financial statements are available to the public.
- The Board approves the annual operating budget, has a process to identify financial risk and manage such risks.
- The following information is available in public documents:

- Most recent three years of annual reports;
- Most recent three years of financial statements and audits;
- A copy of the investment policy;
- Name of Board members;
- Registered Charity Number.
- The Community Residential Hospice completes annual financial statements in accordance with accounting standards.
- The Community Residential Hospice has available for the public the total fundraising revenues, total fundraising expenses and total expenditure on charitable activities.
- Charitable return is completed and returned on time to Canada Revenue Agency.
- All statutory remittances are made.

### **Standard B3. Fundraising**

**Standard statement B3.1** All donations to the Community Residential Hospice are used to support the Hospice’s objects as registered with CRA.

#### **Criteria**

- The Community Residential Hospice performs all its fundraising activities in accordance with federal, provincial and municipal legislation and regulations.
- The Community Residential Hospice prepares and uses official Tax receipts for monetary gifts and in compliance with all regulatory requirements.
- The Community Residential Hospice honours privacy legislation and requests for privacy in relation to donations made.
- Donor records must be maintained by the Community Residential Hospice and kept confidential to the greatest extent possible. Donors have the right to see their own donor record and to challenge its accuracy.
- The Community Residential Hospice respects the rights of donors and potential donors to be removed from solicitations, change the frequency of solicitations and how such solicitations are made.
- Fundraising policies are in place including but not exhaustive of:
  - Tax receipting;
  - Gifts in kind;
  - Donor Recognition;
  - Privacy;
- The Community Residential Hospice discloses all its costs relating to fundraising activities.
- The Board reviews costs relating to fundraising activities annually ensuring no more is spent on fundraising and administration than is required to ensure effective management and resource development.
- Volunteers who solicit or receive funds on behalf of the Hospice must:
  - Act with fairness, integrity and in accordance with all applicable laws;

- Cease solicitation of a prospective donor who identifies the solicitation as unwanted;
- Disclose immediately to the Hospice any actual or apparent conflict of interest or loyalty;
- Not accept donations for the purposes that are inconsistent with the Hospice’s mission.

## **Section C – OPERATIONS**

### **Standard C1. Facility Design and Risk Management**

**Standard statement C1.1** The Community Residential Hospice is a healthcare facility which provides specialized hospice palliative care services in a homelike setting for the residents it serves and their families.

#### **Criteria**

- Comfort, safety and security of all residents as a whole precede an individual’s wishes.
- Design criteria are based on the principles of privacy, security and accessibility using available experts and community resources.
- The Community Residential Hospice is designed to provide a homelike and comfortable environment for each resident and their significant others. Homelike and comfortable includes:
  - Allowing for individual expressions of self;
  - Having no more than 10 residential beds;
  - Having a non-intrusive communication system;
  - Ensuring 24 hour access for significant others as identified by the person.
- The Community Residential Hospice is designed to provide and maintain privacy for each resident and family member and comply with any legislation relating to privacy. Privacy can include:
  - Having a private single room;
  - Individual or shared washrooms specifically for residents;
  - Ensuring controlled access to individual residents’ rooms;
  - Having policies and procedures relating to maintaining residents’ personal privacy and personal information privacy;
  - Ensuring designated space for private and confidential interactions.
- The Community Residential Hospice is designed for maximum accessibility for residents and their families According to accessibility criteria (*Accessibility for Ontarians with Disabilities Act, 2005*)
- To meet the complex multi-dimensional needs of each resident, each room must have access to:
  - A therapeutic scientific surface in order to maintain skin integrity;
  - Medical supplies that are relevant to the demographic population the hospice serves (Children, Adult);
  - Moving and handling equipment;
  - Sharps disposal;

- Communication system in order to “call” for professional assistance;
- The design criteria comply with all federal, provincial and municipal laws and regulations.

### **Standard statement C1.2**

The Community Residential Hospice ensures facility associated risk is minimized.

#### **Criteria**

- The Community Residential Hospice complies with all federal, provincial and municipal legislation and regulations relating to management of a health care facility.
- The Community Residential Hospice has emergency and security systems and a process for regular inspection and testing.
- There are written fire, safety and evacuation plans which are easily accessible to all professional staff and volunteers.
- All professional staff and volunteers have ongoing training on the fire, safety and evacuation plans.
- Policies, processes and training are in place in relation to:
  - Safe food handling;
  - Infection screening and control;
  - Storage and handling of equipment;
  - Routine preventive maintenance of equipment;
  - Safe handling and disposal of sharps and other potentially hazardous materials and substances;
  - Accessibility - non obstructive hallways and exits;
  - Safe and secure storage of medications according to regulatory requirements;
  - Incident and/or occurrence reporting;
  - Safe and comfortable air and water temperature;
  - Occupational Health and Safety:
  - WHMIS training;
  - WSIB reporting.
- There is a provision to accommodate the needs of smokers in the use of outdoor space in compliance with legislation.
- The Community Residential Hospice obtains the appropriate building and property insurance on an annual basis which is reviewed by the Board.

### **Standard C2. Human Resources**

#### **Standard statement C2.1**

Professional and non-professional staff are an integral part of a Community Residential Hospice. Staff should feel valued and empowered in the workplace.

#### **Criteria**

- Community Residential Hospices have comprehensive human resource (HR) policies in place.

- HR policies must comply with employment, workplace health and safety and all other human resource related legislation as applicable in the jurisdiction in which the Hospice operates.
- HR policies are reviewed regularly and available to all staff.
- Job descriptions are in place for all positions in the Hospice.
- Recruitment is through an objective, consistent process that complies with human rights legislation.
- All individuals external to the Hospice who are offered a position of employment receive a letter outlining the terms and conditions of employment.
- An orientation for new employees is in place.
- All employees are given expectations/performance objectives and have an annual performance appraisal completed against said expectations.
- Policies and processes are in place to manage performance issues or concerns.
- A safe work environment is provided including physical safety, emotional safety (free from abuse Bill 168)
- • The Community Residential Hospice has policies and processes in place to deal with conflict management.
- Staffing levels and needs of the Community Residential Hospice are reviewed regularly including;
  - Identifying of critical positions and potential succession planning;
  - Staffing in the event of a pandemic;
  - Training/education needs and budget allocation for training;
- Staff evaluation/satisfaction and feedback mechanisms are in place.
- There is a personnel record for each professional staff who is employed by the Community Residential Hospice
- All records are maintained in accordance with applicable laws and regulations.
- The Community Residential Hospice appoints at a minimum one person who is responsible for the management of the clinical staff, ensuring regulated staff have maintained their registration with the appropriate college, insurance is obtained as needed and staff have the necessary qualifications/certifications to perform in the job.

**Standard C3. Volunteer Involvement.**

**Standard statement C3.1**

Community Residential Hospices are volunteer supported organizations that value and utilize volunteers throughout the organization.

**Criteria**

- The Community Residential Hospice has policies and procedures in place relating to the integration and use of volunteers within the organization.
- The Community Residential Hospice has at least one person who is responsible for, and the appropriate skills for volunteer management.

- Volunteer assignments reflect the mission and purpose of the Hospice and ensure volunteers are engaged in meaningful ways that reflects their abilities, skill set and backgrounds.
- Volunteer recruitment is performed in a fair and equitable, open, transparent and consistent way across the organization resulting in a diverse volunteer database.
- Recruitment includes police checks, reference checks and interviews.
- Volunteer personal information is treated like any other personnel file and kept confidential and secure in accordance with all applicable laws.
- New volunteers are orientated to the organization, informed of the role expectations, given the appropriate training they require to perform the job/task/assignment and a period of probation to meet the desired expectation.
- Volunteers receive a level of supervision appropriate to the task and are given regular opportunities to offer and receive feedback<sup>2</sup> and receive an annual review.
- The contribution of volunteers is acknowledge and recognized.
- Volunteers are welcomed and treated as an integral part of the HR team and thus comply with all related policies for example: confidentiality, infection control and so on.
- Policies are in place to address the risk associated with volunteers practice and safe limits are in place to address such risks.

## ***Section D – QUALITY ASSURANCE***

### **Standard D1. Operations**

#### **Standard statement D.1**

The Community Residential Hospice has a quality management process to regularly review “all aspects of the organization’s activities, resources and functions to assess their effectiveness and revise” as necessary.

#### **Criteria**

- When possible, operations and practice incorporate an evidence-based approach.
- The organization has a quality monitoring and improvement strategy that involves management and staff and is reported to the Board on a regular basis.
- The quality management process involves a number of techniques for example; feedback questionnaires, audit.

### **Standard D2. Individual and Provincial Sustainability**

#### **Standard statement D2.1**

Community Residential Hospices have a comprehensive strategy, individually and collectively as part of the provincial association to maintain sustainability.

#### **Criteria**

- The Community Residential Hospice has a communication and marketing strategy that aligns with the messaging of HPCO.

- The Community Residential Hospice has mechanisms in place to capture and monitor statistics relating to the organization as a whole and individual program that can aid in informing and demonstrating the activities of Hospice to the wider community.
- The Community Residential Hospice provides statistics to HPCO based on the criteria outlined in the statistical reporting guidelines.
- The Community Residential Hospice provides statistical data to external stakeholders as required in order to comply with accountability and other such agreements, where in place, for example: CCAC.

### **Standard D3. Research and Education**

#### **Standard statement D3.1**

The Community Residential Hospice has a process that addresses its involvement in ethical research and education.

#### **Criteria**

- The Community Residential Hospice has policies and processes in place to accommodate student placements from a variety of educational programs.
- The Community Residential Hospice maximizes opportunities to participate in research relating to hospice palliative care.
- The Community Residential Hospice has policies and procedures in place to encourage and accommodate conference presenting/attendance, further education and mentorship.
- The Community Residential Hospice encourages a learning environment for staff and volunteers and provides opportunities to attend in house education.
- The Community Residential Hospice has access to utilize and participate with an ethics committee.

## 4.11 HPC Standards: Other Jurisdictions

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### Standards for Providing Quality Palliative Care for all Australians (4th edition - 2005)

#### Standard 1

Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families' needs and wishes are acknowledged and guide decision making and care planning.

#### Standard 2

The holistic needs of the patient, their caregiver/s and family are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.

#### Standard 3

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

#### Standard 4

Care is coordinated to minimise the burden on the patient, their caregiver/s and family.

#### Standard 5

The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

#### Standard 6

The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

#### Standard 7

The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

#### Standard

Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.

#### Standard 9

Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.

#### Standard 10

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

#### Standard 11

The service is committed to quality improvement and research in clinical and management practices.

#### Standard 12

Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

#### Standard 13

Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

### The Gold Standards Framework (UK)

- The Gold Standards Framework (GSF) in the United Kingdom is a national approach to provide end of life care that focuses on capacity building for frontline, primary care which results in strengthened organization and quality of palliative care
- GSF focuses on;
  - enhanced quality of care which improves health service provider skills and confidence in palliative care, leading to a better care experience for clients;
  - improved communication, coordination and integration across settings of care; and
  - improved outcomes for clients which allows them to live and die where they choose resulting in reduced hospitalizations and cost.
- GSF is based on the 7 Cs of care, regardless of the setting of care: communication, coordination, control of symptoms, continuity of care, continued learning, carer support and care of the dying pathway.
- More specifically it's helps health care organization achieve standards of care that are aligned with quality outcomes for palliative care
- The goal of GSF is to help organizations improve things such as: patients' pain and symptom management, the likelihood of dying in patients' place of choice, avoiding crisis and ED/hospitalization, improved health service provider support and coordination, and improved coordination and communication between providers.
- Implementation of GSF at the local level occurs through GSF Facilitators who are appointed by local care organizations to act as champions for adopting the approach to care. Facilitators are typically family physicians or specialist nurses.
- A national GSF team provides support to the local facilitators by offering workshops, an advice line, a newsletter and web based resources.
- GSF addresses all settings of care by focusing on integrating care across settings and building capacity of the health service providers; it offers training modules to providers through various formats including distance learning and virtual learning opportunities.

Practices also have access to practice tools, guidance documents and are provided with examples of good care.

- Building on the strengths of primary care GSF: systematically identifies palliative patients, assigns a Most Responsible Physician and community nurse for each patient, coordinates inter-professional care through regular meetings, advance care planning with patients, etc.
- By learning to focus on the needs of clients and their families providers learn how to work together to address the patient and family needs
- Initially tried in the oncology population GSF now addressed the needs of clients in their last year of life, regardless of their diagnosis

## 4.12 Template Accountability Agreement between CCACs and Residential Hospices

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*(February 2006; Version 1 – For Residential Hospices that choose to receive Funding from the CCAC)*

### 1.0 INTRODUCTION

#### 1.1 Purpose

1.1.1 The purpose of this Agreement is to clarify the operational, accountability, financial and reporting relationships between the CCAC and the Residential Hospice with respect to Funding provided to the Residential Hospice by the CCAC for the provision of Services pursuant to this Agreement.

1.1.2 The CCAC and the Residential Hospice shall act according to the responsibilities set out for each in this Agreement. This Agreement shall not affect, modify or interfere with the responsibilities of either the CCAC or the Residential Hospice under law.

#### 1.2 Definitions

1.2.1 As used in this Agreement, the following terms have the following meanings:

**Agreement** means this Accountability Agreement;

**Applicable Law** means, with respect to any person, property, transaction, event or other matter, any rule, statute, regulation, by-law, order, judgment, decree, treaty or other requirement having the force of law relating or applicable to such person, property, transaction, event or other matter, and includes where appropriate, any interpretation of a rule, statute, regulation, order, decree, treaty or other requirement having the force of law by any person having jurisdiction over it, or charges with its administration or interpretation;

**CCAC** means the *(Enter Name of CCAC)* designated as a community care access corporation in O. Reg. 33/02 under the Community Care Access Corporations Act, 2001;

**CCAC Case Manager/Coordinator** means an employee of the CCAC who is responsible for assessing eligibility, determining resource needs, developing the Service Plan, providing case management services and evaluating the Service Plan;

**Care Plan** means the individual client care plan that is developed by Residential Hospice Personnel and that is consistent with the Service Plan;

**Funding** means the funding received by the CCAC from the Ministry of Health and Long-Term Care to fund the provision of Services in Residential Hospices;

**Losses** means any and all costs, losses, damages, judgments, claims, demands, suits, actions, causes of action, contracts, or other proceedings of any kind or nature, costs and expenses (including reasonable legal fees and disbursements);

**Ministry** means the Ministry of Health and Long-Term Care;

**Other Professional Services** means physiotherapy, occupational therapy, speech-language therapy, social work and/or dietetic services provided through the CCAC either directly or through contracted service providers to clients residing in the Residential Hospice;

**Personnel** means an employee or independent contractor who is employed or retained by the Residential Hospice to provide nursing or personal support Services to a client residing in the Residential Hospice;

**Residential Hospice** means the Residential Hospice named in this Agreement;

**Services** means the provision of nursing and/or personal support services to support the operation of Residential Hospice beds, but does not include housekeeping services, administrative or overhead costs, or any other services that are offered by the Residential Hospice;

**Service Plan** means the individual service delivery plan developed by the CCAC Case Manager/Coordinator for the provision of CCAC services to an eligible client pursuant to this Agreement.

### **1.3 Guiding Principles**

1.3.1 The CCAC recognizes that the Residential Hospice is a freestanding not for profit hospice that offers end-of-life care in a home-like setting and conducts its operations in accordance with its own mission and philosophy.

1.3.2 The Residential Hospice acknowledges that it is accountable to the CCAC for the administration of the Funding that is received from the CCAC.

1.3.3 The Residential Hospice recognizes its high degree of responsibility to ensure that public funds received from the CCAC are used responsibly and appropriately with integrity and honesty, and in accordance with this Agreement to manage the nursing and personal support needs of clients in the Residential Hospice.

1.3.4 The Residential Hospice shall operate in compliance with the parameters of the Hospice Association of Ontario's Community Residential Hospice Standards, March 2005.

1.3.5 The Residential Hospice shall define the geographic area that the hospice will serve and communicate this to the CCAC.

## **1.4 Currency**

1.4.1 All funding or other payments contemplated pursuant to this Agreement shall be made in Canadian currency and all Funding referred to herein is in Canadian currency.

## **2.0 Term of Agreement**

### **2.1 Effectiveness of Agreement**

2.1.1 This Agreement becomes effective on the date on which the last person signs it and will remain in full force and effect until March 31, 2007<sup>4</sup>, unless it is terminated earlier in accordance with the provisions of Section 14.0 or subsection 10.1.2.

### **2.2 Renewal of Agreement**

2.2.1 The CCAC and the Residential Hospice may, upon their mutual agreement in writing, renew this Agreement on the expiration of the initial agreement term.

## **3.0 Process For Review And Amendment Of The Agreement**

### **3.1 Review of Agreement**

3.1.1 This Agreement is subject to periodic review initiated at the discretion and direction of the CCAC. The Residential Hospice may request that the CCAC review this Agreement.

### **3.2 Amendment of Agreement**

3.2.1 This Agreement may be amended with the agreement of the CCAC and the Residential Hospice. Amendments will be in writing and executed by duly authorized representatives of each party.

3.2.2 The appendices to this Agreement may be amended by the CCAC, in its discretion, at any time and from time to time during the term of this Agreement. The CCAC will discuss any such amendments with the Residential Hospice.

## **4.0 ACCOUNTABILITY RELATIONSHIPS**

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<sup>4</sup> For new hospices, an initial term of one-year is suggested.

- 4.1.1 The CCAC is an *approved agency* under the Long-Term Care Act, 1994. Section 29 of the Act allows an *approved agency* to purchase a community service by a contract from a *service provider*. Under the Long-Term Care Act the hospice is defined as a *service provider* and is required to comply with the Act.
- 4.1.2 The CCAC is accountable to the Ministry to ensure that Funding is flowed to the eligible Residential Hospice in accordance with Ministry funding guidelines and that the CCAC is in compliance with this Agreement.
- 4.1.3 The Residential Hospice is accountable to the CCAC to ensure that Funding received by the CCAC for Services and forwarded to the Residential Hospice pursuant to this Agreement is used solely for the purpose for which the funds were intended and that the Residential Hospice is in compliance with this Agreement.
- 4.1.4 The Residential Hospice has entered into this Agreement with the CCAC solely for the purposes and to the extent set forth in this Agreement and the relationship between the Residential Hospice and the CCAC is and shall, at all times during the term of this Agreement, be that of independent contractors. Nothing in this Agreement shall be construed to constitute the Residential Hospice or any Personnel as a partner, employee or agent of the CCAC for any purpose and neither the Residential Hospice nor any Personnel has any authority to bind the CCAC in any manner whatsoever.

## **5.0 ELIGIBILITY FOR SERVICES**

### **5.1 Eligibility Criteria**

- 5.1.1 To receive Services in the Residential Hospice pursuant to this Agreement, the client must be assessed by the CCAC Case Manager/Coordinator to meet the following eligibility criteria:
  - (a) the client must have a valid Ontario Health Card;
  - (b) the client must be living with a life limiting or life threatening health condition and have a limited life expectancy, regardless of the diagnosis;
  - (c) the client must require nursing and personal support services; and
  - (d) the client must require these services in the Residential Hospice setting.
- 5.1.2 For further clarity, a client cannot be denied access to Services in a Residential Hospice based solely on their diagnosis<sup>5</sup>.
- 5.1.3 The client must reside within the geographic area defined by the Residential Hospice.

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<sup>5</sup> For existing hospices that were established to serve a specific diagnostic group (e.g., clients with cancer), this clause may be removed. All new hospices will be required to comply with this expectation.

5.1.4 Funding from the CCAC may not be used to fund nursing and personal support services for Residential Hospice clients from out-of-province or out-of-country who do not have a valid Ontario Health Card.

## **6.0 SERVICE ROLES AND RESPONSIBILITIES**

### **6.1 Assessment of Eligibility**

6.1.1 The CCAC Case Manager/Coordinator is responsible for:

- (a) determining eligibility for nursing, personal support and all other services provided through the CCAC ;
- (b) identifying clients whose nursing and personal support needs can best be met in a residential hospice; and
- (c) providing information and referral to other community resources as appropriate.

6.1.2 The Residential Hospice is responsible for:

- (a) engaging in discussion with potential clients or caregivers of potential clients to provide information or answer questions about the Residential Hospice;
- (b) ensuring that potential clients or caregivers of potential clients understand that they must be referred to the CCAC for eligibility determination; and
- (c) reviewing all applications for admission to the Residential Hospice and determining the hospice's ability to safely meet the care needs of the potential client prior to accepting the client into the wait list for admission.

6.1.3 For further clarity, the Residential Hospice cannot determine eligibility for nursing and personal support services or admit to the Residential Hospice for nursing and personal support services without the prior approval of the CCAC.

### **6.2 Service Plan**

6.2.1 The CCAC Case Manager/Coordinator is responsible for:

- (a) assessing and determining the service and support needs of the client;
- (b) developing, evaluating and revising of the Service Plan, subject to the consent of the client; and
- (c) referring eligible clients to the Residential Hospice.

6.2.2 The Residential Hospice is responsible:

- (a) making the final determination as to whether the client can be accepted to the Residential Hospice based on the hospice's ability to meet the specific care needs of the client at that time;
- (b) determining the level nursing or personal support required by each client and providing an appropriate staffing complement using the Funding that is received from the CCAC.

### **6.3 Care Plan**

6.3.1 With respect to nursing and personal support services, the Residential Hospice is responsible for:

- (a) developing the individual client Care Plan in consultation with the client and/or caregiver;
- (b) ensuring that the Care Plan is consistent with the Service Plan;
- (c) communicating changes in the Care Plan to the CCAC Case Manager/Coordinator; and
- (d) advising the CCAC Case Manager/Coordinator when the client is discharged or deceased.

6.3.2 With respect to Other Professional Services, the CCAC staff service provider or CCAC contracted service provider is responsible for:

- (a) developing the individual client care plan in consultation with the client and/or caregiver and Residential Hospice;
- (b) ensuring that the care plan is consistent with the Service Plan;
- (c) communicating changes in the care plan to the CCAC Case Manager/Coordinator; and
- (d) advising the CCAC Case Manager/Coordinator when the client is discharged or deceased.

### **6.4 Case Management Services**

6.4.1 The CCAC is responsible for:

- (a) providing a dedicated Case Manager/Coordinator with palliative care expertise to provide case management services to the Residential Hospice; and
- (b) providing ongoing case management services to clients residing in the Residential Hospice.

### **6.5 Wait List Management**

6.5.1 The CCAC and Residential Hospice jointly determine the responsibilities of each organization with respect to the maintenance of a waitlist for eligible clients seeking accommodation with the Residential Hospice. The respective responsibilities of each organization shall be described in Appendix A to this Agreement.

6.5.2 Notwithstanding subsection 6.5.1, the CCAC is responsible for:

- (a) confirming with the Residential Hospice that the client is eligible for Services and that the Residential Hospice is able to meet the client's care needs;
- (b) referring CCAC clients, with the client's consent, to the Residential Hospice and communicating the status of the referral to clients/caregivers; and
- (c) providing ongoing case management services for all clients on the wait list for the Residential Hospice.

6.5.3 Notwithstanding subsection 6.5.1, the Residential Hospice is responsible for:

- (a) notifying the CCAC Case Manager/Coordinator when a Residential Hospice bed becomes vacant;
- (b) making the final determination as to whether the client can be accepted to the Residential Hospice based on its ability to meet the specific care needs of the client at that time;
- (c) managing a waitlist for clients that the Residential Hospice is unable to accommodate at the time that the referral was offered;
- (d) communicating the client's status on the wait list to the CCAC Case Manager/Coordinator;
- (e) making specific admission arrangements with the client/caregiver once the offer of admission has been accepted by the client; and
- (e) ensuring that the Residential Hospice meets the target for occupancy.

## **6.6 Provision of Nursing and Personal Support Services**

6.6.1 The CCAC is responsible for:

- (a) acting as a funding vehicle for the Ministry by providing Funding to the Residential Hospice in respect of the provision of Services to eligible clients in accordance with the service maximums set out in O. Reg. 386/99 under the Long-Term Care Act, 1994;
- (b) reviewing all reports submitted by the Residential Hospice to ensure that the Funding provided to the Residential Hospice is being used as it was intended to be used;
- (c) providing reports to the Ministry as required; and
- (d) ensuring that all accountability and reporting requirements as set out in this Agreement have been met.

6.6.2 The Residential Hospice is responsible for:

- (a) hiring and employing the appropriate Personnel to provide the Services to eligible clients;
- (b) ensuring that the Funding is used to manage the nursing and personal support needs of Residential Hospice clients;
- (c) ensuring that a Registered Nurse (RN) provides on site coverage at the Residential Hospice 24 hours per day, 7 days per week;
- (d) determining the appropriate mix of nursing and personal support staff (over and above the 24 hour per day, 7 day per week RN coverage) required to staff the Residential Hospice and meet the care needs of the clients

6.6.3 The CCAC will authorize and arrange for additional nursing services through its contracted nursing service providers only in exceptional circumstances, such as the provision of specialty nursing consultation services if appropriate, e.g. Enterostomal Therapy. The CCAC will not authorize the provision of additional shifts for routine end-of-life care to individual Residential Hospice clients or for coverage of Residential Hospice staffing shortages due to absence or illness of Personnel.

## **6.7 Provision of Other Professional Services**

The CCAC is responsible for:

- (a) determining the need for Other Professional Services normally provided by CCACs to eligible clients based on CCAC guidelines; and
- (b) authorizing and arranging for the provision of Other Professional Services through a CCAC staff service provider or CCAC contracted service provider.

## **6.8 Provision of Medical Supplies**

6.8.1 The CCAC is responsible for authorizing and arranging for the provision of medical supplies normally provided to eligible clients as per CCAC policies and procedures.

6.8.2 The CCAC will not authorize medical supplies unless they are on the CCAC's approved list of medical supplies.

## **6.9 Provision of Medical Equipment**

6.9.1 The Residential Hospice may use its own capital resources to purchase medical equipment for use by all Residential Hospice clients including but not limited to hospital beds, commodes, walkers, therapeutic surfaces, etc.

6.9.2 The CCAC will authorize and arrange for the rental of medical equipment in circumstances in which the client's individual equipment needs cannot be met by equipment available through the hospice.

6.9.3 The CCAC will not authorize equipment unless it is on the CCAC's approved equipment list.

#### **6.10 Authorization of Drug Benefit Card**

6.10.1 The CCAC Case Manager/Coordinator is responsible for authorizing and arranging for an Ontario Drug Benefit card for eligible Residential Hospice clients.

6.10.2 The CCAC will not fund the provision of medications that are not covered by the Ontario Drug Benefit program.

#### **6.11 Confidentiality of Client Information**

6.11.1 Neither the CCAC nor the Residential Hospice shall use or disclose to any third party any client information except to the extent necessary to perform its obligations under this Agreement and with the consent of the client, or where required by Applicable Law.

### **7.0 ADMINISTRATIVE RESPONSIBILITIES**

7.1.1 The Residential Hospice is responsible for all of its business operations.

7.1.2 The Residential Hospice shall comply with all applicable federal, provincial and municipal laws, rules, orders, regulations and by-laws which, by law, apply to it, including but not limited to the Ontario Human Rights Code, the Employment Standards Act and the Personal Health Information Protection Act, 2004.

### **8.0 CONSULTATION AND COMMUNICATION**

#### **8.1 Obligation to Consult and to Provide Effective Communication**

8.1.1 The CCAC and the Residential Hospice recognize that the timely exchange of information and consultation is essential to the success of discharging their respective responsibilities.

8.1.2 The parties agree that:

- (a) the Residential Hospice shall immediately advise the CCAC, where possible, of issues or events, including contentious matters, which concern or can reasonably be expected to concern the CCAC in the exercise of the CCAC's responsibilities; and

(b) the CCAC and the Residential Hospice shall meet as required to discuss issues relating to the accountability and reporting responsibilities that have been set out in this Agreement, or any other matters of mutual interest.

8.1.3 The CCAC shall be provided with an opportunity to provide input into the Residential Hospice's strategic planning process.

## **9.0 PUBLICITY AND ADVERTISING**

9.1.1 Any publicity or publications relating to the Funding by the CCAC of the provision of Services and all other matters arising out of this Agreement must have the prior written consent of the CCAC.

9.1.2 The Residential Hospice shall at all times acknowledge the support of the Ministry through the CCAC in copies of any and all reports and other written materials and in all advertising and publicity relating to the provision of Services funded by the CCAC, in a format approved by the CCAC. The Residential Hospice shall ensure that the foregoing acknowledgement indicates that the views expressed in the materials are the views of the Residential Hospice and do not necessarily reflect those of the CCAC.

## **10.0 FINANCIAL ARRANGEMENTS**

### **10.1 Residential Hospice Funding**

10.1.1 The CCAC shall receive and administer the Funding allocated from the Ministry for the Residential Hospice.

10.1.2 The Residential Hospice acknowledges and agrees that the term of this Agreement is expressly subject to the CCAC's Memorandum of Understanding with the Ministry and Funding provided to the CCAC by the Ministry for the purpose of funding the Services. Accordingly, in the event that the Ministry terminates or reduces Funding, or in the event that the Ministry no longer provides Funding to the CCAC for the Services, or any portion thereof, that are the subject matter of this Agreement, the CCAC shall be entitled to terminate this Agreement. Provided that the funding is made available to the CCAC for such purpose, the CCAC will make reasonable efforts to provide transition services to the extent practicable where Funding for Services to the Residential Hospice is decreased or terminated by the Ministry.

10.1.3 The Residential Hospice shall use such Funding solely for the purpose of hiring and employing the appropriate Personnel to provide the Services to eligible clients.

### **10.2 Flow of Funds**

10.2.1 The CCAC shall flow the Funding to the Residential Hospice in equal installments once every month up to the maximum allocation provided to the CCAC from the Ministry for the provision of nursing and personal support services provided to eligible clients.

10.2.2 Any part of the Funding that has not been used or accounted for by the Residential Hospice during the fiscal year shall be returned to the CCAC within 60 days of the end of the fiscal year.

### **10.3 Withholdings, Remittances, Etc.**

10.3.1 The Residential Hospice shall be solely responsible for doing or ensuring the withholding, collection or payment of any and all taxes, source deductions, premiums, contributions and remittances of any nature, including any interest or penalties or other amounts, to any applicable governmental authorities, arising from any payments made by the CCAC to the Residential Hospice or from any payments made by the Residential Hospice to any Personnel, and the CCAC shall not be responsible for doing or ensuring any such withholding, collection or payment. The Residential Hospice shall keep the CCAC indemnified from and against any Losses whatsoever which the CCAC may suffer or incur as a result of the Residential Hospice's failure to comply with its obligations hereunder.

### **10.4 Financial**

10.4.1 Without limiting the obligations of the Residential Hospice contained elsewhere in this Agreement, the Residential Hospice shall be responsible for:

- (a) Collecting data and maintaining records to support the provision of Services to clients under this Agreement and its receipt of Funding and payment for Services hereunder;
- (b) Providing to the CCAC quarterly financial reports which account for the Residential Hospice's administration of the Funding within 30 days after the end of the CCAC's fiscal quarter of June 30<sup>th</sup>, September 30<sup>th</sup>, December 31<sup>st</sup> and March 31<sup>st</sup>;
- (c) Ensuring that all financial records with respect to the administration of the Funding are available to the CCAC upon request; and
- (d) Complying with the CCAC's detailed Funding and Billing requirements as set forth in Appendix B.

### **11.0 INDEMNIFICATION**

11.1.1 The Residential Hospice shall indemnify and safe harmless the CCAC, and its employees, independent contractors, subcontractors and agents from and against all claims, losses, damages costs, demands, expenses, contracts, actions for other proceedings, made, sustained, brought, prosecuted, threatened to be brought or prosecuted, in any manner based upon, occasioned by or attributable to anything done or omitted to be done on

the part of the Residential Hospice, its directors, officers, employees, independent contractors, subcontractors or agents in connection with the responsibilities of the Residential Hospice or its directors, officers, independent contractors or agents in connection with this Agreement.

- 11.1.2 The indemnity set out in 11.1.1 shall not extend to any claims, losses, damages, costs, demands, expenses, contracts, actions for other proceedings of any kind or nature to the extent that they are based on, occasioned by, or attributable to anything negligently done or omitted to be done by the CCAC or its employees, independent contractors, subcontractors or agents in connection with this agreement.
- 11.1.3 The Residential Hospice's ability to indemnify or reimburse the CCAC shall not affect or prejudice the CCAC from exercising any other rights under the Applicable Law.
- 11.1.4 The Residential Hospice shall protect itself from and against all claims that might arise from anything done or omitted to be done by the Residential Hospice or its directors, officers, employees, independent contractors, subcontractors or agents under this Agreement, and more specifically all claims that might arise from anything done or omitted to be done under this Agreement where bodily injury, including personal injury, death or property damage, including the loss of use thereof, is caused.

## **11.2 Insurance**

- 11.2.1 For the purpose of Section 11.1.4, and without restricting the generality of that Section, the Residential Hospice shall maintain in full force and effect during the term of this Agreement, at its own expense, a policy of comprehensive general liability insurance in form and substance reasonably acceptable to the CCAC, with prior consultation, providing coverage for a limit of not less than five million (\$5, 000,000.00) dollars for each occurrence of a claim of bodily injury (including personal injury), death, or property damage, including loss of use thereof, that may arise directly or indirectly from the acts or omissions of the Residential Hospice or its Personnel in connection with the provision of Services funded by the CCAC under this Agreement. All insurance shall show the CCAC as an additional insured in the policy.
- 11.2.2 The Residential Hospice shall submit to the CCAC upon notice by the CCAC proof of the insurance coverage in the form of a certificate and a copy of the relevant portion of the insurance policy incorporating the terms and clauses referred to in Sections 11.1.1 and 11.1.4. Such coverage shall be kept current throughout the term of this Agreement and any subsequent renewals to this Agreement.
- 11.2.3 The Residential Hospice shall use reasonable efforts to ensure that all Personnel providing Services that are funded by the CCAC under this Agreement maintain in full force and effect, during the term of this Agreement, the appropriate malpractice liability insurance or its equivalent coverage.

## **12.0 REPORTING REQUIREMENTS**

### **12.1 Financial Reports**

12.1.1 The Residential Hospice shall prepare and submit to the CCAC quarterly financial reports within 30 days after the end of each fiscal quarter and will include the following information:

- (a) total Funding received from the CCAC during the applicable reporting period;
- (b) total amount of CCAC Funding spent on direct nursing services during the applicable quarter;
- (c) total amount of CCAC Funding spent on direct personal support services during the applicable quarter;
- (d) the variance between total Funding received and total amount spent on nursing and personal support services;
- (e) total hours of direct nursing services purchased using CCAC Funding;
- (f) total hours of direct personal support services purchased using CCAC Funding;
- (g) percentage of total program costs funded by the CCAC;
- (h) average number of nursing service hours per client;
- (i) average number of personal support service hours per client; and
- (j) total number of clients served during the applicable quarter.

12.1.2 The Residential Hospice shall use the Financial Reporting Template in Appendix C to report to the CCAC.

### **12.2 Key Performance Indicator Monitoring Reports**

12.2.1 The Residential Hospice shall prepare and submit to the CCAC quarterly key performance indicator monitoring reports within 30 days after the end of each fiscal quarter and will include the following information:

- (a) number of clients served by diagnosis during the applicable quarter;
- (b) average length of stay in the Residential Hospice in days;
- (c) average occupancy rates;
- (d) number and type of client/caregiver complaints related to nursing services; and
- (e) number and type of client/caregiver complaints related to personal support services.

12.2.2 The Residential Hospice shall prepare and submit to the CCAC within 30 days after the end of the fiscal year a summary of the results of formal and informal surveys of client and/or caregiver satisfaction, and any follow-up to such surveys.

12.2.3 The Residential Hospice shall use the Key Performance Indicator Reporting Template in Appendix D to report to the CCAC.

## **13.0 RECORDS AND AUDITS**

- 13.1.1 The Residential Hospice shall keep and maintain separate books of account and financial records, including copies of all payments issued to Personnel, respecting the administration of all amounts paid in respect of the provision of Services funded by the CCAC under this Agreement and shall maintain such books and records for a period of seven years from the termination or expiry of this Agreement, or such longer period as is required by law.
- 13.1.2 The Residential Hospice shall, at the termination or expiry of this Agreement keep at its premises, all reports, documents and files relating to the clients who receive Services and shall maintain such reports, documents and files for a period of:
- (a) Ten years following the date of the client's death or the last contact with the client, for clients that are aged 18 years or older: or
  - (b) Ten years following the date that the client became or would have become 18 years old, for clients aged less than 18 years old at the time of death or last contact; or
  - (c) Such longer period as is required by law
- 13.1.3 The Residential Hospice authorizes the CCAC and its agents, upon 24 hours notice and during normal business hours, to visit the Residential Hospice's premises to inspect and copy any books, records, invoices, reports, documents and files in the possession or under the control of the Residential Hospice relating to this Agreement and the provision of Services funded by the CCAC hereunder.
- 13.1.4 The CCAC's rights of inspection under this Agreement include the right to perform an audit, either by the CCAC or the Provincial Auditor.
- 13.1.5 If any such inspection or audit discloses an understatement or overstatement of Funding properly due to the Residential Hospice for any period, the amount of any such deficiency or excess shall be paid over to the party to whom such amount is owing, within fifteen days after the receipt of the inspection or audit report, in each case together with interest at the Prime Rate plus one percent on such amount from the date such amount was originally due or overpaid, as the case may be, to the date of payment. For purposes hereof, "Prime Rate" means the prime commercial lending rate of interest, expressed as an annual rate, quoted by the Bank of Montreal from time to time as the rate that it charges to its preferred commercial customers in respect of commercial loans made in Canada.
- 13.1.6 The Residential Hospice shall submit, to the CCAC, the annual audited financial statements of the Residential Hospice for each of the Residential Hospice's financial years that occur during the Agreement term. The Residential Hospice shall provide its

audited financial statements to the CCAC no later than 90 days after the end of the applicable financial year. Where financial statements are not audited, the unaudited financial statements shall be submitted after review by a qualified accountant together with a review engagement report.

## **14.0 TERMINATION OF THE AGREEMENT**

### **14.1 Termination by the CCAC**

14.1.1 In addition to the termination rights referred to in Section 10.1.2, this Agreement may be terminated by the CCAC or will be terminated automatically, as the case may be, in any of the following circumstances:

- (a) by the CCAC on the giving of thirty days prior written notice if the Residential Hospice is in breach or default in the performance of any of its obligations hereunder and such breach or default is not remedied to the satisfaction of the CCAC within such thirty day period; or
- (b) automatically and immediately in the event that:
  - a. the Residential Hospice becomes bankrupt or insolvent; or
  - b. a receiving order is made against the Residential Hospice; or
  - c. a resolution is passes or other action taken for winding-up or dissolution of the Residential Hospice; or
  - d. the Residential Hospice files any notice under or derives benefit from any statute relating to bankruptcy or insolvent debtors or the orderly payment of debts; or
  - e. the Residential Hospice ceases operation as a Residential Hospice.

### **14.2 Termination by the Residential Hospice**

14.2.1 This Agreement may be terminated by the Residential Hospice, or will terminate automatically, as the case may be, in any of the following circumstances:

- (a) on the giving of sixty days prior written notice if the Residential Hospice opts out of the envelope funding method for the provision of nursing and personal support services pursuant to this Agreement; or
- (b) on the giving of thirty days prior written notice if the CCAC is in breach or default in the performance of any of its obligations hereunder and such breach or default has not been remedied within such thirty day period; or
- (c) automatically and immediately in the event that:
  - a. the CCAC becomes bankrupt or insolvent; or
  - b. a receiving order is made against the CCAC; or
  - c. a resolution is passed or other action taken for winding-up or dissolving the CCAC ; or

- d. the CCAC files any notice under or derives benefit from any statute relating to bankruptcy or insolvent debtors or the order payment of debts.

### **14.3 Effect of Termination**

14.3.1 Within 90 days following the termination or expiry of this Agreement, the parties shall each perform an accounting of amounts funded and expenditures made for Services. The termination of this Agreement shall not affect the liability of either party for amounts due or accruing due to the other party at the date of termination, or amounts funded but not spent, which amounts shall be debts that shall continue to be binding and enforceable obligations. Either party may set off against any amounts due to the other party, any amounts properly due and owing or refundable to such party, as the case may be. Furthermore, the indemnities herein provided for the benefit of the CCAC shall survive any termination or expiry of this Agreement and shall continue in full force and effect for the benefit of the CCAC.

### **14.4 Misappropriation of Funding**

14.4.1 If the CCAC terminates this Agreement due to the Residential Hospice's usage or expenditure of any Funding for any purpose other than the provision of Services pursuant to the Service Plans in the manner authorized and agreed to by the CCAC, the CCAC may in addition to all other rights conferred upon it under this Agreement or in law or at equity, require the Residential Hospice to immediately pay the CCAC an amount equal to the funds used or spent by the Residential Hospice for the purpose not authorized or agreed to by the CCAC.

### **15.0 NOTICE**

15.1.1 Any notice, consent or other communication (hereinafter referred to as "notice"), required or otherwise, to be given by a party to this Agreement to the other, shall be deemed to have been sufficiently given seven days after such notice has been mailed, postage prepaid, or on the due date of receipt, where such notice has been delivered by hand or facsimile transmission. Any such notice shall be addressed:

- (a) in the case of a notice to the CCAC to: (enter contact name and contact information); and
- (b) in the case of a notice to the Residential Hospice to: (enter contact name and contact information).

15.1.2 Any party may from time to time change its representative, address or facsimile number by notifying the other party with the notice thereof in accordance with the provisions of Section 15.1.1.

### **16.0 GENERAL PROVISIONS**

## **16.1 Entire Agreement**

16.1.1 This Agreement and the Schedules and Appendices hereto constitute the entire agreement between the parties pertaining to the subject matter hereof and supersedes all prior agreements and understanding, collateral, oral, or otherwise. There are no other agreements among the parties in connection with the subject matter of this Agreement, except as specifically set forth in this Agreement and the Schedules and Appendices hereto.

## **16.2 No Waiver**

16.2.1 No failure by a party to insist upon strict performance of any covenant, agreement, term or condition of this Agreement, or to exercise any right or remedy consequent upon a breach thereof, shall constitute a waiver of any such breach or of such covenant, agreement, term or condition. No waiver of any breach shall affect or alter this Agreement, but each and every covenant, agreement, term and condition of this Agreement shall continue in full force and effect with respect to any other then existing or subsequent breach thereof.

## **16.3 Assignment**

16.3.1 The Residential Hospice may not assign this Agreement without the prior written consent of the CCAC which consent may not be unreasonably withheld. This Agreement shall be deemed to be assigned, and the prior written consent of the CCAC required in the event of a change in effective control of the Residential Hospice. For the purposes of the foregoing, "change in effective control" means the transfer or issue by sale, assignment, transmission on death, encumbrance, issuance from treasury, operation of law or otherwise, of any shares, voting rights or interest which would result in any change in the identity of the person or entity exercising, or who might exercise, effective control of a corporation or partnership and, in the case of a partnership, includes a change in any of its partners.

16.3.2 The CCAC may in its sole discretion, assign the Agreement without the consent of the Residential Hospice.

## **16.4 Successors and Assigns**

16.4.1 This Agreement shall enure to the benefit of and be binding upon the parties hereto and their respective successors and permitted assigns.

## **16.5 Further Assurances**

16.5.1 Each party shall from time to time and at all times hereafter do such further acts and things and execute such further documents and instruments as shall reasonably be required in order to fully perform, carry out and give effect to the purposes and intent of this Agreement.

## **16.6 Confidentiality**

16.6.1 The Residential Hospice agrees that all information regarding the CCAC must remain strictly confidential. The Residential Hospice agrees that neither it, nor its directors, officers, employees, agents, or contractors shall divulge information communicate to it or acquired by it or disclosed by the CCAC, its employees, agents, or contractors in the course of carrying out the Services required to be provided herein, without the prior written consent of the CCAC save and except to the extent necessary or usual in the course of providing such Service. Furthermore, the Residential Hospice shall not use, at any time during the term of this Agreement, or thereafter, any of the information acquired by the Residential Hospice during the course of carrying out the Services provided herein for any purposes other than the purposes authorized in writing by the CCAC.

## **APPENDIX A**

### **Responsibilities of the CCAC and the Residential Hospice With Respect to the Maintenance of a Waitlist for Eligible Clients**

## **APPENDIX B**

### **Detailed Funding and Billing Requirements**

## **APPENDIX C**

### **Financial Reporting Template**

## **APPENDIX D**

### **Key Performance Indicator Reporting Template**

#### **Percentage of clients served by diagnosis during the applicable quarter**

- Number of clients with malignant and non-malignant diagnoses served during the applicable quarter divided by the total number of clients served during the applicable quarter X 100

#### **Average length of stay in the Residential Hospice in days**

- Total number of days spent in Residential Hospice (all clients) in the applicable quarter divided by the total number of clients served during the applicable quarter

#### **Occupancy rates**

- Total number of beds available to be filled during the applicable quarter.

- Average number Residential Hospice beds filled during the applicable quarter, i.e. the number of beds available times the number of days in the applicable quarter divided by the total number of Residential Hospice beds actually filled during the applicable quarter

**Number and type of client/caregiver complaints related to nursing services**

**Number and type of client/caregiver complaints related to personal support services**

**Client and/or caregiver satisfaction (to be reported at year-end only)**

- A description of the results of formal and informal surveys and any follow-up to surveys

### 4.13 Provincial Palliative Care Policy and Regulation Barriers (HPCO, March 2013)

	Issues & Barriers	Solutions	Policy & Regulations
1.	Need for a sustainable provincial HPC structure that communicates regularly with the MOHLTC and provides recommendations related to province wide HPC services	<ul style="list-style-type: none"> <li>• One Provincial HPC Association</li> <li>• A broader Provincial HPC Coalition consisting of all provincial associations that support the principle of quality end-of-life care for all Ontarians.</li> <li>• The Provincial Association as the Secretariat for the HPC Coalition</li> <li>• Linkage to the CHPCA, the QEOLCC and other Provincial HPC Coalitions</li> <li>• Linkage to the local HPC Networks</li> </ul>	
2.	Need for a sustainable LHIN wide/regional HPC structure – HPC Networks	<ul style="list-style-type: none"> <li>• Broad system design,</li> <li>• Coordination and integration of services at a system level,</li> <li>• Monitoring and assessment of community needs,</li> <li>• Promotion of service innovation</li> </ul>	<ul style="list-style-type: none"> <li>• Clearly establish the mandate and role of the HPC Networks consistent with MOHLTC EOL Care Strategy</li> <li>• Clearly establish a Network linkage with the MOHLTC to ensure provincial consistency and equitability for HPC</li> <li>• Networks needs to be incorporated into the LHIN structure to be recognized as accountable and viewed as neutral regional system planners for HPC</li> <li>• Increase the annualized \$70,000 per LHIN area to support HPC Networks and their vital work</li> <li>• Infection Control Networks may be considered as a model example</li> </ul>

	<b>Issues &amp; Barriers</b>	<b>Solutions</b>	<b>Policy &amp; Regulations</b>
3.	Need provincial consensus and agreement of the HPC model Lack of a Provincial HPC Strategy	<ul style="list-style-type: none"> <li>• Adopt the CHPCA Model to Guide HPC</li> <li>• Increase public awareness ~ develop a provincial campaign</li> <li>• HPC needs to incorporate progressive life limiting illnesses</li> <li>• Develop a Provincial HPC System Design that is aligned and implemented by the Regional HPC Networks</li> </ul>	<ul style="list-style-type: none"> <li>• Develop a Provincial HPC Policy</li> </ul>
4.	Lack of a coordinated provincial approach to HPC No mandatory provincial service delivery framework Lack of a local coordinated systems-wide approach to HPC	<ul style="list-style-type: none"> <li>• Develop a LHIN wide HPC program coordinated by the HPC Networks</li> <li>• Identify and develop a mandatory provincial service delivery framework that is responsive to population based needs;</li> <li>• Standardize admission criteria to access palliative care services;</li> <li>• Population based registry (e.g. like diabetes registry);</li> <li>• Leverage existing HPC research, demonstration projects, pilots, reports, activities etc., within Ontario and elsewhere to develop next steps</li> <li>• Ensure that the paediatric population is included in the system-wide approach to HPC</li> <li>• Ensure that the plan recognizes and includes cultural and linguistic diversity</li> </ul>	<ul style="list-style-type: none"> <li>• Authorization from MOHLTC, Accountable to MOHLTC, Accountable to the LHINs</li> <li>• Formal linkage with the Integrated Client Care Project</li> <li>• Formal linkage with the ER/ALC strategy</li> <li>• Formal linkage with Aging at Home Strategy</li> <li>• Formal linkage between the LHINs and the HPC Networks;</li> <li>• Integrate funded HPC services into a LHIN-wide HPC program;</li> </ul>

	<b>Issues &amp; Barriers</b>	<b>Solutions</b>	<b>Policy &amp; Regulations</b>
		<p>across the province</p> <ul style="list-style-type: none"> <li>• Ensure the plan recognizes both urban and rural issues</li> </ul>	
5.	<p>Vulnerability of HPC Services and resources (both physical and human) Lack of adequate financial supports for HPC Services and resources (Summary Report PPCIP, March 2008, p.69)</p>	<ul style="list-style-type: none"> <li>• Development of HPC teams across the province in all care settings, especially community and acute care</li> <li>• Sustainability and growth of residential hospices across the province</li> </ul>	<ul style="list-style-type: none"> <li>• Dedicated, adequate core funding for HPC services and resources inclusive of residential hospices and the shared care outreach teams</li> <li>• Clarity on definition and standards of all HPC programs</li> </ul>
6.	<p>Family physician/Family Health Teams accountability Billing codes – General Physician of Oncology negate family physician billings; Alternate Palliative care Payment Plan; “orphaned” patients</p>	<ul style="list-style-type: none"> <li>• Local engagement of family physicians</li> <li>• Local capacity building for primary care</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC/LHIN accountability agreements with Family Physicians and Family Health Teams</li> <li>• OMA/MOH agreement language</li> <li>• Mechanism for orphaned patients to be accepted by family physicians/FHTs/CHCs ~ OMA/MOH agreement</li> <li>• Strengthen the Alternate Palliative Care Payment Plan for Physicians enabling to integrate with the development of community HPC secondary level expert teams</li> <li>• Define and share accountability for primary care;</li> </ul>

	<b>Issues &amp; Barriers</b>	<b>Solutions</b>	<b>Policy &amp; Regulations</b>
7.	<p>Lack of performance measurement, accountability, quality indicators to drive change</p> <p>Lack of a common database – patient health information</p> <p>Lack of real time clinical data (Summary Report PPCIP, March 2008, p.69)</p> <p>Time lag for death data (Summary Report PPCIP, March 2008, p.69)</p>	<ul style="list-style-type: none"> <li>• The Ontario Cancer Registry (OCR) is a highly reliable data source for disease incidence and death data; its death records have a confirmed date and cause of death, both from death certificates. However, it also has a considerable time lag – about 2-3 years - for its death data. As a result, although this outcome is of keen interest to government, it is not possible to obtain the information to understand the impact of programs in a timely way. It is not clear how difficult it would be to improve this system</li> </ul>	<ul style="list-style-type: none"> <li>• Adoption and reporting schedule for the National palliative care scorecard</li> <li>• HPC information technology and documentation needs are incorporated in the Provincial e-Health Strategy</li> <li>• Policy work be undertaken in the time lag for death data to understand the issues and suggest alternatives.</li> </ul>
8.	<p>Lack of skilled interdisciplinary HPC staff</p>		<ul style="list-style-type: none"> <li>• Human resource plan with regional considerations</li> <li>• Regulation of Personal Support Workers (PSWs)</li> </ul>
9.	<p>Request for Proposals/contract management for palliative care services (nursing, SW, PSW) within the CCAC structure – inconsistency across Ontario</p>		<ul style="list-style-type: none"> <li>• Change in CCAC regulations to include adequate HPC standards, performance expectations and educational qualifications and service hours;</li> <li>• Standards consistent across the province</li> <li>• Specialized HPC requests of proposals across Ontario</li> </ul>
10.	<p>Number of hours per patient available for community services and in LTC settings</p>		<ul style="list-style-type: none"> <li>• Change in CCAC regulations</li> <li>• Review of the LTC funding formula to reflect an increase of care hours for residents especially for those who are in need of HPC services</li> <li>• Consistency and equal access across Ontario</li> </ul>

	<b>Issues &amp; Barriers</b>	<b>Solutions</b>	<b>Policy &amp; Regulations</b>
11.	<p>Inter-disciplinary collaborative practice – IPE, standards for education</p> <p>Lack of continuity and training</p> <p>Lack of coordinated, accountable, standardized HPC education aligned with LHIN wide HPC systems planning/system designs</p>		<ul style="list-style-type: none"> <li>• Defined competencies &amp; scopes of practice in conjunction with professional colleges and regulating bodies</li> <li>• Working with formal education facilities to incorporate an inter-professional model of HPC education</li> <li>• Establish HPC education standards for Ontario</li> <li>• Align the Community and Facility Interdisciplinary HPC Education service to the geographic LHIN boundaries and to local system planning</li> <li>• Align the Palliative Pain and Symptom Management Consultation Service to the geographic LHIN boundaries and to local system planning</li> <li>• Align HPC Physician Education Service to the geographic LHIN boundaries and to local system planning</li> </ul>
12.	<p>Lack of public information on death and dying</p> <p>Lack of information to education families</p>	<ul style="list-style-type: none"> <li>• Work with the LTC Associations in Ontario to create and implement a education strategy for families of residents living in LTC Homes</li> <li>• Local implementation to be included in the HPC program</li> </ul>	<ul style="list-style-type: none"> <li>• Provincial Advance Care Planning Strategy</li> <li>• Local implementation to be included in the HPC program</li> </ul>
13.	<p>Lack of seamlessness for home death pronouncement</p>		<ul style="list-style-type: none"> <li>• Provincial Pronouncement Policy</li> <li>• Coordinated at the LHIN level by the HPC Networks</li> <li>• Enable Registered Nurses certify death in expected death situations – work with the</li> </ul>

	<b>Issues &amp; Barriers</b>	<b>Solutions</b>	<b>Policy &amp; Regulations</b>
			College of Nurses of Ontario to implement

Reference Documents:

- CCO PPCIP Report (March 2008)
- Provincial Think Tank Proceedings (June 2009)
- Hospice Palliative Care in Ontario: The Way Forward Survey Report (March 2010)

## **4.14 Residential Hospices Working Group: Themes from Focus Groups**

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The RHWG identified the need to host a series of Focus Groups to provide collaborative, system-wide input to inform the full breadth of potential care delivery models and to build a vision for residential hospices that reflects common priorities and interests among partners. The RHWG hosted a series of eight Focus Groups with the following stakeholders:

1. Residential Hospices Interest Group
2. Palliative End of Life Care Network Leads and LHIN Palliative Care Leads
3. The Research Community
4. Hospice Palliative Care Provincial Steering Committee
5. Clients and Caregivers
6. Diverse Communities and Rural Geographies
7. Health Links
8. First Nations Communities

Each Focus Group provided suggestions that helped to shape and validate the final report the RHWG.

### **Methodology for Focus Groups**

A small task group was assembled to provide input on the structure, content, and participant list for the Focus Groups. Additionally, Dr. Mary Lou Kelley from Lakehead University, a prominent researcher in rural and First Nations communities, along with members of her team provided advice on and facilitation of the Diverse Communities and Rural Geographies and First Nations Focus Groups.

The Focus Groups followed a similar structure; participants were provided with materials and background information prior to attending the Focus Group. At each event the purpose of the Focus Group was outlined, an overview of the proposed model for the End of Life Continuum was presented, along with the 7 recommended Action Items. Presentations were tailored to the Focus Groups. Following the presentations facilitators led the participants through a discussion to provide them the opportunity to respond to the questions related to their Focus Group. Notes were taken during the Focus Groups to capture the discussion and recommendations for the RHWG resulting in note for each Focus Group.

Upon completion of all Focus Groups the notes for each Focus Group were reviewed and responses were organized using a modified affinity diagram approach, grouping individual responses into themes that had natural affinity with one another. Once the affinity process was completed for each Focus Group the responses were themed across all Focus Groups.

## Focus Group Themes and Impact

Generally speaking, participants of the Focus Groups were pleased with the recommendations, models and action items proposed by the RHWG. Focus Group participants also expressed their support of the ability to allow for flexibility at the local level with respect to the proposed recommendations.

The themes contained in the Table 1 emerged from the across the eight Focus Groups as a result of the modified affinity diagram process. The themes appear in alphabetical order along with a summary of the responses related to them and the resulting actions, if any.

Focus Group Themes	Summary of Responses
<b>Caregivers:</b>	<ul style="list-style-type: none"> <li>• Agreement with the increased focusing on normalizing care outlined in the report; emphasizing earlier identification in the end of life trajectory</li> <li>• Patient/caregiver education needed to normalize EOL care</li> <li>• Patients/caregivers need help to navigate the system</li> <li>• Health service provider education on EOL care is also required</li> <li>• Need for bereavement services should be highlighted</li> <li>• The importance of the family and informal care givers was highlighted along with a need for respite care</li> </ul>
<b>Flexibility and Integration:</b>	<ul style="list-style-type: none"> <li>• Strong agreement with the approach of a flexible and integrated model.</li> <li>• The idea of “customized standardization” was embraced</li> </ul>
<b>Health Links Specific Suggestions:</b>	<ul style="list-style-type: none"> <li>• Variation with respect to Health Links level of involvement which, rightly so, depended on location</li> <li>• Keen interest in collaboration with Health Links to minimize duplication and maximize offerings to patients/caregivers</li> </ul>
<b>Health System Change:</b>	<ul style="list-style-type: none"> <li>• Focused on a desire to shift the setting of care for EOL patients to hospice or the community, where appropriate, instead of acute care settings</li> </ul>
<b>Implementation Suggestions/ Issue:</b>	<ul style="list-style-type: none"> <li>• Comments were related to implementation suggestions and issues that are beyond the scope of the Report however still very important</li> </ul>
<b>Leveraging Existing Strengths:</b>	<ul style="list-style-type: none"> <li>• Strong desire to leverage resources that exist in communities across the province</li> <li>• Recognition that every community has strengths that can be leveraged to strengthen end of life care</li> </ul>
<b>Meeting the Needs of Diverse</b>	<ul style="list-style-type: none"> <li>• The need for culturally and linguistically sensitive techniques and communication skills were reiterated</li> <li>• In remote communities, especially First Nations communities, participants</li> </ul>

<b>Communities:</b>	<p>noted the lack of critical health service infrastructure</p> <ul style="list-style-type: none"> <li>• The tension between federal and provincial responsibilities was identified as a potential barrier to access to appropriate care with the First Nations communities.</li> </ul>
<b>Residential Hospice Funding:</b>	<ul style="list-style-type: none"> <li>• Issues related to the funding of residential hospices were highlighted</li> <li>• Policy issues related to sustainability, distribution and patient population of hospices were highlighted</li> </ul>
<b>Strengthening Long-Term Care:</b>	<ul style="list-style-type: none"> <li>• Encouraged the exploration of building capacity in long term care homes to provide EOL care</li> </ul>
<b>Technology Requirements:</b>	<ul style="list-style-type: none"> <li>• Barriers related to access to technology in remote communities and lack of common electronic medical records were identified</li> </ul>

**Table 1. Themes from Eight Focus Groups**

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