Strengthening Ontario's End-of-Life Continuum: Advice Regarding the Role of Residential Hospices

Final Report of the Residential Hospices Working Group
Transmittal

We are pleased to present the report *Strengthening Ontario’s End-of-Life Continuum: Advice Regarding the Role of Residential Hospices*. The Workgroup has reached a common consensus on the identified priorities and action, as well as capacity and planning models we believe will strengthen the end-of-life continuum of care in Ontario and optimize the role of residential hospices. In order to ensure that this work is responsive to the needs and interests of diverse populations, geographies, and care settings, and representative of the full breadth of potential care delivery models, the Working Group engaged with sector stakeholders and key informants through a number of focus group consultations.

This advice falls under Ontario’s *Declaration of Partnership and Commitment to Action* (the Declaration). Building on the Declaration, this report outlines the strong and integrated system of end-of-life care in Ontario that we aspire to create. As Working Group members representing the ministry, LHINs, home care, palliative care, residential hospice care, clinical and research sectors, we share the belief that the actions outlined in this document will significantly strengthen Ontario’s end-of-life continuum of care for Ontario residents and their families, by improving patient, caregiver and provider experience, enhancing quality of life prior to death, alleviating complex bereavement after death, reducing avoidable emergency visits and hospitalizations, and better supporting people to die in their location and circumstances of choice.

Our hope is that the Hospice Palliative Care Provincial Steering Committee, and all its broader partner organizations, associations and networks, will be able to use this advice as they work to ensure all patients approaching end-of-life, as well as their caregivers, have access to the care they need and are supported to achieve their highest quality life and death. It is intended that sector stakeholders can use this tool as a reference point as they consider ways in which they can improve their delivery practices to this population. Similarly, the ministry and LHINs can utilize this advice to inform any future decisions regarding policy, funding or expansion of residential hospices in this province as well as LHIN planning, integration and service options through the development of their regional palliative programs/networks.

On behalf of the members of the RHWG, the Co-Chairs from the RHWG are pleased to share this work:

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\(^1\) The RHWG would also like to acknowledge the past secretariat support provided by Emily Hellyer and Deanna Bryant.
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EXECUTIVE SUMMARY

High quality care at the end-of-life supports the quality of living and dying for the sickest Ontarians and improves the well-being of their partners in care, both before and after death, recognizing that death and loss is inevitable and universal. In this report, the focus for strengthening Ontario’s end-of-life continuum is the 100,000 Ontarians “approaching end-of-life” within any one year (that is, people approaching their last year of life, living with advanced or late stage serious life-limiting illness, or facing imminent death). Consistent with Ontario’s vision and roadmap for improving palliative care outlined in the Declaration of Partnership, the advice in this report is offered in response to the following specific challenges:

- **Public Awareness**: Public knowledge and understanding about palliative and end-of-life care is limited and is not experienced as “normal”.
- **Access**: Not every-one who can benefit from a palliative philosophy of care receives it.
- **Person and Family-Centred Care**: The wide diversity of patient and family needs and circumstances, as well as unique setting or geographical characteristics, make organizing care around patient and family preferences and needs at end-of-life more challenging.
- **Capacity and integration of end-of-life care**: The availability and integration of appropriate care for all patients approaching end-of-life in all settings can be strengthened and optimized.
- **Accountability**: Residential Hospices, along with other providers of end-of-life care, need to be more fully integrated and accountable within an organized system of care.

Residential Hospices are an important component within a planned, comprehensive, system-wide continuum of end-of-life care that should be organized based on essential design principles:

- Broad recognition of aging, death and loss as normal, inevitable and universal;
- Is organized around the patient and caregiver journey, not just services and care settings;
- Targets the whole end-of-life population;
- Focuses on patient well-being and whole citizen care in the context of their communities;
- Provides early and equitable access to exemplary care across a variety of sectors and services, including long-term primary, community and residential care; complex chronic disease management; geriatric care; and/or palliative care service streams;
- Supports effective community capacity development to make creative use of existing health and community assets;

*These principles acknowledge that the care people receive is more important than the place and that the nature of leadership is more important than the type of individual or organization.*
The following priorities have been identified to strengthen Ontario's end-of-life continuum and optimize the role of residential hospices:

1. Prospectively find patients approaching end-of-life (the 1%) within communities and take action based on their needs.
2. Offer personalized, patient and family-centred care that empowers patients and families to take ownership of their palliative and end-of-life journey.
3. Enable patients approaching their last year of life to receive exemplary care through flexible “personalized” teams within integrated service systems.
4. Work within communities to normalize aging, death and loss.
5. Strengthen and optimize residential and hospital inpatient capacity for people facing imminent death.
6. Ensure strong provincial and regional oversight and accountability.
7. Use technology as an accelerator for connected, integrated systems.

In addition, specific advice regarding evidence-based planning capacity and resource allocation models in the following areas is offered:

- Health Service Utilization: End-of-Life Service And Resource Planning
- Team-Based Care and Coordination Models
- Complexity Model and Best Evidence Delivery Characteristics

It is noted that many of the necessary elements already exist in the many communities. Because of different starting points however, it is also acknowledged that the journey may look different in different communities.
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CONTEXT

Declaration of Partnership 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

To advance the vision of the Declaration of Partnership and Commitment to Action [the Declaration], Ontario’s roadmap for improving the quality and value of palliative care in this province, the Ministry of Health and Long-Term Care (ministry), Local Health Integration Networks (LHINs), Community Care Access Centres (CCACs), Hospice Palliative Care Ontario and other sector partners are working collaboratively as the Residential Hospice Working Group to provide advice on strengthening the continuum of care and support for Ontarians at the end-of-life and on how best to optimize residential hospices to support those who cannot be cared for at home but do not require hospital care in their last days and weeks of life.

This advice fits under the Declaration priorities by elaborating upon the policy, planning and practice considerations that are unique to end-of-life care. The Working Group’s advice will inform the development in Ontario of a comprehensive strategy on palliative and end-of-life care that ensures all patients have access to the care they need, well as any future decisions regarding policy, funding or expansion of residential hospices in this province. The advice provided in this report in this regard is intended to be direction-setting and evolutionary. Any new steps and actions which are approved based on this advice will be confirmed through policy and/or incorporated into provincial or regional implementation priorities and plans.

Care at the end-of-life supports the quality of living and dying for the sickest Ontarians and improves the well-being of their families, both before and after death, recognizing that death and loss is inevitable and universal. It is not reserved to patients who have ceased active treatment, nor limited to planning for a “good death”. Mounting evidence confirms that a lack of access to palliative and end-of-life care can lead to physical suffering, greater emotional distress, pointless or painful interventions, and even a shortened lifespan. By reframing end-of-life care as support for “life and living”, we acknowledge the importance of this philosophy of care and its delivery within the context of the communities in which a patient resides and interacts as central to improving outcomes for frail and complex populations, alongside early identification of need, patient and family-centred (or advanced) care planning, and high quality treatment and delivery approaches. Recognizing that most patients and families say they would prefer death at home if the needed supports were there, consideration of an optimized role for residential hospices requires us to also look at the related community and team-based
supports and services which help prevent or delay patients and their care partners from needing to seek services from a residential hospice or hospital, if this is not their preferred choice.

**NOTES REGARDING TERMINOLOGY:**

“Palliative Care” is a philosophy of care that aims to relieve suffering and improve the quality of living and dying and is appropriate for any individual and/or family living with a life threatening illness from the time of diagnosis onwards, at any time they are prepared to accept this type of care and support. Palliative care enhances other types of care, including restorative or rehabilitative care, or may become the total focus of care; it can be provided while patients are also receiving curative treatments. Palliative care includes but can be distinguished from end-of-life in that it encompasses the entire patient and family journey as they adapt to living with a life-limiting illness. This terminology builds upon the description of palliative care outlined in the *Declaration of Partnership*.

“End-of-life” is used to describe the last year or so of a person’s life, as well as the last days and weeks of life, and is synonymous with advanced/late stage serious life-limiting illness. For 90% of people, end of life unfolds in two stages:

- People are “approaching their last year of life” when they or their providers would not be surprised if their death were to occur in the next 12 months or they have other characteristics associated with an advanced or late stage of a life-limiting illness or significant frailty
- People are facing “imminent death” when they are expected to die within the next few weeks, days or hours – although this final stage may be difficult to recognize in many people with advanced life-limiting illness

**Communities** are a social unit of any size that share a common identity or purpose. For the purposes of this paper, the term “community” should be understood to mean a specific, tangible, geographically delineated area. But within this macro-community, it also means the “nested” functional and virtual human communities that co-exist within the same shared space which are made up of people from a wide range of health, social, cultural, economic and political spheres.

- In successful communities, individuals will be able to self-identify with multiple communities synergistically and simultaneously. The strongest geographical communities are those where a plethora of social, cultural, and other common interest communities also exist and thrive.
- “Community” geographical boundaries for measurement and planning purposes should at a minimum be aligned to Health Links boundaries; but there is also room for local and neighborhood models that cascade up within a Health Links boundary.
- In all human communities, intent, belief, resources, preferences, needs, risks, and a number of other conditions may be present and common, affecting the identity of the participants and their degree of cohesiveness.

**Smaller Communities** as used in this paper means any one of the following:

- ‘Rural’ communities in Ontario are those 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.
- ‘Northern’ communities are comprised of 10 territorial districts (145 municipalities) in Northern Ontario: Kenora, Rainy River, Thunder Bay, Cochrane, Algoma, Sudbury, Timiskaming, Nipissing, Manitoulin, and Parry Sound.
- ‘Remote’ communities are those without year-round road access, or which rely on a third party (e.g. train, airplane, ferry) for transportation to a larger centre.

*[Rural and Northern Health Care Framework – Final Report (MOHLTC, undated, Page 7)]*

**Patient** with end of life care needs: includes adults, seniors and children, recognizing patients have a wide range of diverse socioeconomic, psychosocial, cultural, spiritual, developmental and other needs.

**Home** is the physical structure (e.g. a house, apartment, a long-term care home or other shelter) that is the usual residence of a person.
TARGET POPULATION

100,000 Ontarians who are approaching the end-of-life within any one year

The focus for strengthening Ontario’s end of life continuum is people “approaching end-of-life” (that is, approaching their last year of life or facing imminent death).

End-of-life generally unfolds in stages within the patient and family overall palliative care journey - which starts from the time of diagnosis with a life-limiting illness through to death, and extends to bereavement following death. Specifically, end-of-life describes the last year or so of a person’s life, as well as the last days and weeks of life, and can be synonymous with advanced/late stage disease. Adults and children are “approaching end-of-life” when they have:

- Advanced, progressive, incurable conditions;
- General frailty and co-existing conditions that mean they are expected to die within 12 months;
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition;
- Life-threatening acute conditions caused by sudden catastrophic events.²

The Palliative Care Journey

About 1% of the population dies each year.³ We should therefore expect to find within any given year, about 100,000 Ontarians who meet our target population definition (adjusted against 2012 population levels).

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² UK General Medical Council, 2010 cited in GSF Prognostic Indicator Guidance 2011
³ Ibid
CURRENT STATE SCAN

Population and Service Characteristics

Target Population Profile
Based on past and projected mortality trends\(^4\), we expect about 100,000 adults and children to die in Ontario in 2015 and beyond - and therefore be included in our target population as they begin to enter into their last year of life. The following table provides an overview of some of their characteristics:\(^5\)

<table>
<thead>
<tr>
<th>Age breakdown</th>
<th>75,000 seniors</th>
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<tbody>
<tr>
<td></td>
<td>25,000 children and adults</td>
</tr>
<tr>
<td>Typology - Trajectory of death</td>
<td>30,000 cancer</td>
</tr>
<tr>
<td></td>
<td>27,000 frailty/dementia</td>
</tr>
<tr>
<td></td>
<td>27,000 organ failure</td>
</tr>
<tr>
<td></td>
<td>17,000 other</td>
</tr>
<tr>
<td>Location (balance of year prior to death)</td>
<td>20,000 LTCH</td>
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<tr>
<td></td>
<td>80,000 community/primary care (often with multiple discrete episodes of inpatient care)</td>
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It is important to note that the relative breakdown of the typology of disease and death trajectory are not stable and will change over time. The continuation of a 10 year trend in year-to-year reductions in Canadian rates of death for cancer, heart disease, and stroke\(^6\) combined with demographic aging and projected increase in rates of dementia, will affect the proportion of frailty/dementia deaths relative to other trajectories in the future. It is also noted that the typology of deaths specific to children is somewhat different from that of adults and seniors, with a much higher proportion of sudden or accidental deaths followed by cancer compared to the other trajectories.

<table>
<thead>
<tr>
<th>Location of death (last hours or days of life prior to death)</th>
<th>40,000 acute care (plus 5,000 ER)</th>
</tr>
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<td>Based on a retrospective analysis of 87,000 deaths in Ontario in 2011/12(^7)</td>
<td>7,000 CCC</td>
</tr>
<tr>
<td></td>
<td>17,000 home</td>
</tr>
<tr>
<td></td>
<td>3,000 community hospice (with planned capacity for about 8,000 to 9,000 once all approved beds developed)</td>
</tr>
<tr>
<td></td>
<td>15,000 LTCH</td>
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This chart has not been adjusted to account for current numbers of deaths. Location of death breakdown is not stable, and is changing over time to some degree. For example, there has been a small year over year decline in deaths in hospital across Ontario and increase in deaths in the community over the past few years. As LHINs add more hospice beds and teams in the community, this trend should continue and potentially become more pronounced.

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\(^4\) In 2011/12, 90,771 Ontarians died and in 2012/13, 93,755 Ontarians died (Stats Can). The trend to increasing number of deaths each year is expected to continue until about 2060.

\(^5\) For more detailed evidence synthesis, see the RHWG Environmental Scan

\(^6\) Statistics Canada *Trends in Mortality Analysis*, 2014

\(^7\) 2011/12, recorded in the Ontario Vital Statistics
The Canadian Palliative Care Model = A Cancer Model.

Although many of the patients approaching their last year of life are amongst the sickest and highest cost health care users in Ontario, currently, only about 30% of patients (mostly patient with advanced cancer) appear to be identified as “palliative” and receive on-going palliative care and support in the community, including support to die in their preferred place of death, such as their home or in a residential hospice.

- While cancer represents 29% of all deaths (with projected year over year decline in the future), most palliative care is delivered to patients with cancer.
- Frail patients, those with dementia and/or advanced organ failure tend to be under-represented in designated palliative care programs and services, relative to their numbers within the overall target population.

System Palliative “Map”

The current array of services and referral pathways is experienced as confusing and difficult to navigate for patients (and even providers), which may contribute to the challenges experienced by patients and families in accessing palliative and end-of-life service.

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9 Palliative Care Client Journey: Map and Issues, May 2010 by Dianne Cairney MMDC Consulting Inc. for OACCAC, Integrated Client Care Project
Role of Residential Hospices (currently)

Residential hospices serve the subset of patients facing imminent death – currently, access targets those living with a life threatening progressive or terminal illness with a pre-determined prognosis and life expectancy who understand that resuscitation and other life sustaining interventions are not offered.  

An examination of the profile of patients reveals residential hospices currently serve patients:
- Suffering primarily from cancer;
- Mostly seniors, but at the younger end;
- Requiring mostly assisted or total care, acknowledging that admission is based on a number of factors, including clinical acuity and patient and family needs and preferences; and
- Needing care for a short period of care immediately prior to death.

For the majority of patients in residential hospices, their approaching death and death trajectory is predictable as evidenced by the low survival rate and short length of stay (approximately 18 days).

Challenges at End-of-Life

“No Canadian should die alone, no Canadian should die afraid, and absolutely no Canadian should die in pain”.  

Redefining palliative care and “normalizing” care at the end-of-life

Public knowledge and understanding about palliative and end-of-life care is limited
- In a recent survey, 70% of respondents said that they are “not at all knowledgeable” about palliative care; surprisingly, many believe it hastens death.  
- Most patients and many physicians tend to only associate palliative care with the cessation of treatment and impending death. As a result, patients balk at the mention of it, and physicians are slow to refer them to it. The use of palliative care in outpatient settings, where patients are a bit more stable and have a longer prognosis is tremendously low.”

Aging, loss and bereavement is everyone’s responsibility, not just healthcare
- Most attention is given to institutional and professional relationships rather than the personal relationships between dying, loss, and the related impact on families and the community.

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10 Community Residential Hospice Standards A.2 Access to Hospice  
11 For detailed evidence and data, see the RHWG Environmental Scan, Nov 2014  
12 Dr Louis Francescutti, Canadian Medical Association president, quoted in “Redefining Palliative Care” by Kate Lunau, Maclean’s Magazine, March 18, 2014.  
13 Survey reported in New England Journal of Medicine (Dec 2014)  
14 “Redefining Palliative Care” by Kate Lunau, Maclean's, Mar 18, 2014  
www.macleans.ca/society/health/redefining-palliative-care
Not every-one who can benefit from a palliative philosophy of care receives it

Patients are not being identified with palliative and end-of-life care needs early enough, which is compounded by the following clinical and system challenges:

- Predicting needs is more important than precise clinical prognostication of impending death or estimates of length of survival.¹⁵
- “Clinical prediction of survival has been found to be erroneous (defined as more than double or less than half of actual survival) 30% of the time in expert hands. Two thirds of errors are based on over optimism and one third on over pessimism.”¹⁶
- “The advanced cancer trajectory may be significantly different from that of other advanced illnesses. Diseases resulting in chronic organ failure, such as chronic obstructive pulmonary disease, congestive heart failure, and end-stage liver disease, tend to run a more fluctuating course and result in death in a less predictable time.”¹⁷
- Palliative and end-of-life care (relief of suffering and support to improve quality of life) should start earlier. Palliative care “is most often accessed only after life-prolonging treatments have failed, when they could be delivered side-by-side.”¹⁸
- Hospice Palliative Care (HPC) eligibility and service criteria may itself reinforce a narrow cancer focus. Reductionist criteria used to refine and manage services and settings may be limiting to patients and families in terms of their need for care. For example, eligibility for hospice care may be based on survival prognosis; service criteria and prioritization is based on PPS score (i.e. the degree to which the patient is physically immobilized) and not the broader needs of patients and families; and access to some services may be restricted depending on whether the patient is receiving active treatment.

Organizing Care Around Patient Preferences and Needs

Responding to Each Patient’s Uniqueness and Diversity

- Patient and family needs (both health and non-health related), characteristics, preferences, and values are extremely varied and so diverse as to defy a ‘one size fits all’ approach.
- There are many individual circumstances that may make the provision of end-of-life care more challenging, including being a child, having developmental challenges, mental health issues, behavioural or cognitive impairment, living in poverty, living alone, being homeless, having language barriers.
- Culture and religion may shape an individual’s values and norms regarding various dimensions of end-of-life care. The multicultural makeup of Ontario suggests the need for

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¹⁵ UK General Medical Council, 2010 cited in GSF Prognostic Indicator Guidance 2011
¹⁸ Maclean's (Mar 18, 2014) www.macleans.ca/society/health/redefining-palliative-care
culturally sensitive end-of-life communication and decision-making to meet the needs and expectations of a growing immigrant population.\textsuperscript{19}

- There is also wide diversity in patients’ and families’ abilities to mobilize their own personal support and social networks.

\textit{Preferences for home death}

- People can’t be supported to have a home death unless they have a home, have people at home to care for them, and want to die at home – a significant number of our target population do not have access to these supports.\textsuperscript{20}

- Preferences for home death may be influenced by culture, the person’s values and beliefs, the fear of becoming a burden to family, the type and level of resources that are available to them in their home, and may change over the course of the end of life journey.
  
  - For example, it is noted that patients at home with a surviving spouse are less likely to die in inpatient care and those who are defined as their own main caretaker are more likely to do so.\textsuperscript{21} Determinants of home deaths in cancer patients receiving home-based palliative care include: patients who had moderate/high nursing and personal support costs compared to patients with lower costs; patients who lived with someone compared to patients who lived alone; and patients who had a higher propensity for a home death.\textsuperscript{22}

\textit{Caregiver Needs}

- Families and volunteers provide 80\% of the care required by children, adults and seniors with long-term health or other significant care needs. Depending on the family context and circumstances, it may be difficult for caregivers and families to keep someone at home. Some caregivers may also be reluctant to ask for needed help, which may affect their own health.

- Caregivers need support in coordination and navigation of formal, informal and social care.

- Too many caregivers experience high levels of distress. For example, 1 out of 5 caregivers of patients receiving home care report feeling distressed and overwhelmed\textsuperscript{23} Evidence shows that caregiver vulnerability and distress increases with patient complexity, up to a point.

\textit{Socioeconomic Needs}

- Socioeconomic deprivation is a major determinant of where, when and how people die.\textsuperscript{24}

\textsuperscript{19} McMaster Citizen’s Brief (Nov 2013), “Improving Access to Palliative Care in Ontario”

\textsuperscript{20} For detailed evidence and data, see the RHWG Environmental Scan, Nov 2014

\textsuperscript{21} Dunphy et al (1990), “A Comparison of hospice and home care patients”

\textsuperscript{22} Motiwala et al (2006)” Predictors of Place of Death for Seniors in Ontario: A Population-Based Cohort Analysis”

Also see OHTAC Mega-Analysis of End of Life Care in Ontario for a thorough examination of evidence regarding determinants of place of death

\textsuperscript{23} Hirdes, J (Feb, 2011), Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions, Change Foundation

\textsuperscript{24} NHS National End of Life Care Programme (Feb 2012) “Deprivation and death: Variation in place and cause of death” cited from www.endolifecare-intelligence.org.uk
• Special attention needs to be paid to people living in poverty and in the poorest neighborhoods – such factors may be overlooked in strict acuity-based admission policies.
• Most families make a significant financial contribution to care for someone at home; this can be especially problematic for families who are facing financial hardship.

Unique setting characteristics making care more challenging
• There is wide variation in resource availability in different communities and geographies.
• People who are dying in rural, remote and northern areas may have relatively less access to formal palliative care services and other health infrastructure than their urban counterparts. Barriers to accessing palliative care for residents in small communities may include geographic isolation, a shortage of human resources, and lack of palliative care education and training for generalist health care providers.\(^\text{25}\)
• Similar limitations may be experienced in specific settings such as shelters and correctional facilities.

Capacity and integration of end-of-life care
Availability and integration of appropriate care in all settings
• The care a patient receives may vary greatly depending on setting.
• There are significant gaps in how patients approaching their last year of life are identified in primary care and home care, especially patients with advanced, serious illness such as late-stage frailty/dementia and organ failure.
• Hospital regulations, privacy issues, providers that lack relevant training and a historically curative focus may make the delivery of effective in-patient end-of-life care difficult.\(^\text{26}\)
• Palliative care of dying residents of long-term care homes may be reduced to late-stage pain and symptom management when it is initiated within a few days or hours of death.\(^\text{27}\)
• Sectors remain stubbornly separate, despite best efforts of many providers to collaborate.
• Ontario’s Declaration commits to a fluid delivery model that integrates medical care, chronic disease management and palliative care from diagnosis until death and through to bereavement, but this model is not widely experienced in practice. While slowly improving, current health and palliative care programs and services are fragmented.
• There are limited models and practical means to advance true shared ownership, accountability and real collaboration. While this is improving through Ontario’s Health Links, the interface between community, health and social care systems is also not clear and may be difficult for patients and families to navigate. There is room for greater sharing of information, advice and best practices that can be adapted across settings.
• There is also variation in practice and models within similar care settings – it is unclear in many cases whether such variation constitutes an acceptable degree of experimentation and innovation, or represents a preventable gap in quality. Even within and across

\(^{27}\) Cable-Williams, B (2014) “Awareness Of Impending Death In Long-Term Care Facilities”
palliative, end-of-life and hospice services, establishing effective communication channels and coordinating service provision can be challenging.

- A capacity-building approach may be needed to improve the delivery and integration of end-of-life care in primary and community care, long-term care homes, hospice and hospital-based services.

**Residential Hospices are not fully integrated within an organized system of care**

*Within the current system model, residential hospices are neither fully in nor fully out.*

- Geographical distribution of residential hospice beds is uneven across the province, as a result of the nature of volunteer efforts and fund-raising for residential hospices.
- There are significant sustainability challenges associated with the current funding framework for residential hospice including current funding model and fundraising requirements, capital costs associated with free-standing models, and the sustainability of models, especially in small communities.
- There is variation in residential hospice relationships with CCACs and a lack of an accountability relationship with the LHIN.
- There is insufficient evidence and data regarding residential hospice care specifically as well as population outcomes and impact.
- Within the residential hospice sector, there is variation between different model “clusters”, variation in the physician model at hospices and variable understanding of best practices and quality of care across residential hospice and palliative care services.
- There is both variation and insufficient understanding of how to optimize relationships between residential hospice, hospital services, and primary care and community providers.
- Challenges are noted for smaller communities in the application of rigid standards that do not match the small populations and geographical distribution served in these communities.
FUTURE STATE SCAN: Compass Points

Residential Hospices are an important component within a planned, comprehensive, system-wide Continuum of End-of-Life Care that is organized based on essential design principles, including:

- Broadly recognizes aging, death and loss as normal, inevitable and universal.
- Is organized around the patient and caregiver journey, not just services.
  - Extends from diagnosis through treatment to death and bereavement.
  - Ensures that “once you’re known, you never become not known”.
  - Promotes health and “normalizes” of care at the end-of-life.
- Targets the whole end-of-life population not just service-based care.
  - Unique end-of-life strategies and service baskets may be required for patients with different trajectories of need including short period of evident decline (e.g. cancer); long-term limitations with intermittent serious episodes (e.g. organ failure); prolonged dwindling (e.g. frailty and dementia); and death resulting from sudden or unexpected events.
  - Is not limited to patients who formally receive palliative services.
- Focuses on patient well-being and whole citizen care in the context of their communities.
  - Availability of community systems that provide genuine and authentic support during the 95% of time patients and families are not with their healthcare provider.
- Provides early access to exemplary care across a variety of sectors and service, including long-term primary, community and residential care; complex chronic disease management; geriatric care; and/or palliative care service streams.
  - Core Commonality: ALL patients with advanced, late stage or complex chronic disease(s) should receive care that is proactive, holistic, patient and family-focused, centering on quality of life and symptom management issues, and delivered by an integrated interprofessional team in a coordinated, continually-updating, care plan.
  - Positions end-of-life care within a chronic illness/frailty continuum.
  - Equitable: Consistent high-quality, high-value services should be delivered equitably to similar populations according to evidence, leading practices, and professional standards. All services should demonstrate value for money. Similar services targeting patients with similar levels of need should be more consistently and equitably funded, regardless of the specific care setting or sector in which the service is delivered.
  - Complexity/need vs prognosis as a criteria for specialist intervention.
  - Balances predictable supply, demand and preference considerations to extent possible
  - Provides a standard of care that is exemplary while building capacity, sustainability and knowledge through collaborative, shared care models with primary and community care at the centre.
- Supports effective community capacity development to make creative use of existing health and community assets.
  - Community as a partner: leadership and facilitation is available for community development, health promotion, and capacity-building.
Community and population-centred system that is organized for collaborative impact (with common agenda, shared measurement, mutually reinforcing activities, continuous communication, and backbone support organization).

- The care people receive is more important than the place.
- The nature of leadership is more important than the type of organization or individual.

New approaches should be evaluated and shared to the extent they measurably improve patient and family outcomes and experiences with care, provider and system outcomes resulting in:

- Improved patient and family experience assessed through self-reported experience measures.
- Improved symptom management and quality of life for patients and populations measured by quality of life, health status (for example, pain or depression) and subjective perceived health.
- Improved system performance and sustainability reducing avoidable resource use and improving efficiency.
ADVICE REGARDING TACTICS AND PRIORITIES

Most Promising Areas of Focus

1. Prospectively find patients approaching end-of-life (the 1%) within communities and take action based on their needs

- Early identification of patients with advanced, serious illness or palliative care needs and matching them to an appropriate model of care has significant benefits to patient and family quality of life and experience, as well as significant benefits to the system. If we were better able to identify more people approaching end-of-life early on in their journey, whatever their diagnosis, they would be more likely to receive well-coordinated, high quality care – although the methods and model of care might look different for different populations.

- Although some deaths are unexpected, most people with advanced or late stage illness or frailty approaching the end of life can be reliably identified based on certain triggers, including “the surprize question”, general indicators of decline, and/or specific clinical indicators related to certain conditions.

- At a patient level, it is important for providers within primary care, community, LTCHs, geriatric services as well as disease specialists like oncologists to be able to identify the 1% of patients within their programs and practices who are likely to die in the next year– to plan with them the care they want to receive over the last stages of their journey and to begin connecting them to the full range of supports and services they will need:
  - Ideally, for most patients, this will not be a new conversation but a continuation of a conversation that started at the time of their diagnosis with a life-limiting illness.
  - Continued exploration of the use of appropriate assessment and identification tools, including standardized frailty measures, in primary, community, LTCHs and specialty care will help providers ensure that more of their patients are appropriately identified.
    - For example, through Ontario’s INTEGRATE project, an early identification tool-kit with checklists and prompts is being developed based on the Gold Standards Framework, along with an evaluation of its use by selected teams in primary care and regional cancer centres.
  - Once patients are identified as approaching end-of-life, organizations should take steps to systematically keep track of them through use of registries or other tracking tools. The aim is for patients to be easily be identified and found in the system, which decreases the likelihood of patients “falling through the cracks”.
  - Such tools and processes should contribute to strengthening Ontario’s provincial system of palliative and end-of-life care – once successfully demonstrated and evaluated, support and oversight for standardization across regions is desirable.

- At a population level, a structured approach to prospectively identifying the cohort of frail patients approaching the end-of-life based on their level of need should be developed.

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28 UK General Medical Council, 2010 cited in GSF Prognostic Indicator Guidance 2011
While there is substantial retrospective information available regarding people who died, there are limited prospective models to better identify both palliative and frail cohorts approaching end-of-life. Through the Residential Hospice Working Group, collaborative research has been initiated to prospectively identify population-level early warning flags and cohort models that will be applicable to the whole end-of-life population, not just those patients receiving palliative services or having a prognosis of death.

- Use of such algorithms, once developed, will facilitate improved accountability, outcome measurement, quality improvement, and better inform actions and system-level strategies to optimize care and reduce unnecessary resource use.
- Additional population sub measures might distinguish between patients who are receiving formal palliative care services and other frail or advanced disease patients, as well as permit patients to be grouped according to their mortality risk index or instability of end stage disease.

- These approaches are consistent with the Provincial Steering Committee priority of ensuring early identification and access to supports and care options.

2. Offer personalized, patient and family-centred care that empowers patients and families to take ownership of their palliative and end-of-life journey

- Patients and families best understand the realities of their condition, the impact of disease and its treatment on their lives, and how services can be better designed and organized to help them. Today’s health consumers are increasingly engaged and aware and want better ways to help themselves and should be involved in the co-design of new approaches and tools.
- Patients are empowered through education and accessible information. Surveys reveal that Ontarians do not well understand the provision of hospice palliative care approaches and what services and supports might be available to them. All Ontarians should have access to high visibility public gathering spaces where can go to get their questions and concerns answered, as well as easy access to virtual and print information repositories and resources. In addition, opportunities to engage in broader public dialogues to build awareness about palliative care, and advanced care planning should be encouraged.
- To offer relevant and meaningful support to patients and families throughout their journey, the system must engage patients and families according to their preferences, on the terms they are willing to accept, and at a level they are comfortable with. The provision of care, especially as people approach their last year of life, must be closely aligned with their values, goals and preferences to support them in achieving the highest quality life and death possible. This includes putting the person and their partners in care in charge of decisions, not the provider, and reframing the conversation— for example, by asking what the patient and family want, not telling them what they need.

29 See RHWG Environmental Scan for details of survey data
30 Snowdon, A (Feb 2014) It’s All About Me: The Personalization of Health Systems, Ivey International Centre for HealthCare Innovation
• Care arrangements must then be customized according the individuals needs and circumstances, as well as patient and family preferences and goals. There should be clear processes to routinely record patient and family goals and preferences while recognizing that these change over time. It should also explicitly assess and address the needs of informal caregivers for support.

• All providers should use consistent, standardized processes for early advance care planning as an on-going part of care planning. This means that care planning processes should support the patient’s highest quality of life possible at present while also anticipating and planning for the future. The patient’s careplan should be continually revisited and updated as part of routine, on-going processes of care.

• As part of the support which is provided to them, patients and families can benefit from being offered access to formal and virtual education and training, peer support, coaching, navigation support and assistance in mobilizing their personal networks, and rapid access to advice and assistance when needed through a clear and simple communication and contact protocol.

• Patient and families can be supported through patient-oriented technology that helps them organize and manage their own care, stores and keeps track of their own personal health information, and enables them to more easily communicate their experience and sense of progress across their providers.

• An important part of providing person-centred care is ensuring that teams and front-line providers have access to the information and supports they need to customize their care processes to meet the specific needs of the wide range of unique and diverse populations they serve within their communities – such as children, patients and families with specific cultural or spiritual preferences and norms, language or literacy barriers, developmental challenges, mental health issues, behavioural or cognitive impairment, those living in poverty, living alone, homeless, etc. - and to ensure their ability to communicate effectively with patients and families of all kinds is optimized.

• Patient and family input should be sought through the use of standardized surveys and experience measures to inform system and program level quality improvement and learning.

• Where appropriate, patients and families may be invited to help co-design person-centred programs and services and reports, where such a role is possible in their circumstances.

• Recognizing that there may be additional financial costs borne by families in supporting a death at home, consideration for the provision for self-directed funding or more flexible needs-based access to support would also better enable the on-going delivery of care at home.

• Governments should give attention to streamlining processes to ensure humane, person and family-centred support can be provided. Challenges may be compounded where different ministries or levels of government are involved. For example, Social Service/Ontario Works financial coverage for funeral, burial and body washing is covered in some regions but not others. Having a streamlined process to ensure the timeliness of financial approvals under this program, especially where cultural norms require the funeral
to occur quickly after death, is important to minimize additional unnecessary stress on families at this time.

- Continued collaboration and engagement across government, business, and provider sectors can help in supporting caregivers who are also workers.

3. **Enable patients approaching their last year of life to receive exemplary care through flexible “personalized” teams within integrated service systems**

**Patient-Centred “Personalized” Teams**

- The flexible formal and informal organization of people around the patient and family over the course of their end-of-life journey is critical to the provision of high quality, sustainable end-of-life care, recognizing that in most cases, formal health services and teams provide only a small fraction of the day to day supports required by patients and their families.

- Patient and family needs (both health and non-health related), characteristics, preferences, and values are extremely heterogeneous and so multifarious as to defy simple programmatic solutions and pathways. This, as well as differences in resource availability in different communities and geographies and wide diversity in patients’ abilities to mobilize their own personal support and social networks, suggests that customized and personalized teams are the ONLY model capable of comprehensively advancing patient and family goals, ensuring support in addressing their most important non-health related problems, responding appropriately to diversity, and reducing unmet medical, social, psychological and other needs in a sustainable and respectful manner.

- Patients and families should be engaged as partners in how their teams and care plans are created, organized and managed, to the extent they wish to participate. Patients and families should be asked what help they want, who should be included on their “personalized” team, what the roles and responsibilities of each unique provider should include, and who their preferred interface should be in terms of the overall team “quarterback” role.

- A patient’s team will be inclusive of both “health” and “non-health” organizations and interests, inclusive of both publicly-funded services and private and volunteer services, and inclusive of both formal and informal partners.

- With the patient’s permission, the broader “team” should have access to a single, inclusive plan of care that is organized around the patient and family goals and preferences, that is derived from reliable, consistent assessment data and information, and is based on shared knowledge of resources and assets to help optimize their quality of life.

- The personalized team will evolve and change over the course of the patient and family journey, and as their specific needs, goals and preferences change - allowing for the provision of services to come in and out depending on the specific, time-limited needs or new, emerging goals of the patient and family.
Building Capacity in Primary Level Care Settings and Volunteers

- Most palliative care is, and can be, provided by primary providers – provided they have adequate support, appropriate education, training and skills development that includes access to consultation and mentorship, training in use of standardized best evidence tools and pathways, and access to shared care delivery models with palliative specialists when appropriate based on the needs of their patients.

- Building on the strengths of primary care, standard processes should be used to systematically identify patients approaching their last year of life in primary care practices, assign a core team of most responsible providers for each patient, coordinate interprofessional care through regular meetings, and engage in advance and on-going care planning with patients and families.

- Palliative care competencies should be considered part of core services across primary care practices, including Family Health Teams (FHTs), Community Health Centres (CHCs), other primary care models, and non-specialized home and community programs and services.

- A core set of primary level front-line providers can be mobilized to support patient and family needs throughout their whole end-of-life journey – including physicians/primary care providers, nursing, palliative volunteers, non-palliative community providers, pharmacists, and residential service workers, if applicable. Core primary providers should remain with the patient and family throughout their journey, sharing care as appropriate with more specialized providers, teams and care settings on a time-limited, as needed basis, based on shared accountability for patient, population and system outcomes.

- Volunteers are highly valued partners who play a key role in supporting patients and families in their own personal end-of-life journeys and contribute significantly to the formal care team – like other providers, their role within an integrated system needs to be supported through recognition, training, and capacity building approaches.

Formal In-home Palliative Care Teams

- In-home interprofessional teams that care for individuals approaching end-of-life, both at home and in long-term care homes, reduces the expected healthcare costs and improves health outcomes for these patients and their families. The population impact of this intervention is potentially large, especially the potential for reducing acute care utilization and improving in-home palliative services. For example the Ontario Health Technology Advisory Committee (OHTAC) recommends that all patients who receive palliative care services have access to interprofessional, team-based, integrated, and patient-centred care at the end of life, provided directly to them across multiple venues. Optimally and where feasible, OHTAC recommends that this care be provided by the same team. 31

- In-home interprofessional teams will often provide the core capacity, resources and expertise within a patient’s personalized team.

- There is an emerging body of evidence as well as several excellent models in practice in Ontario that should be considered in terms of the building capacity to deliver effective

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31 OHTAC (July 2014) Mega-Analysis Series – End of Life Health Care in Ontario pg 12
palliative care programs within communities\textsuperscript{32}, and shared care partnerships between specialist palliative care teams and primary care providers.\textsuperscript{33} A change guide has been developed which will help communities to develop strong, evidence-based teams.\textsuperscript{34}

- Similar capacities should also be developed in specialized geriatric teams, and other kinds of teams dedicated to patients requiring complex care management.

**Integrated Systems of Services and Resources**

- Through LHIN regional planning processes and Health Links, there is an expectation that local health care infrastructure will be utilized to the extent possible to support a system approach to palliative and end-of-life care that integrates services, resources, supports and care settings spanning entire frailty/chronic disease management trajectory. It is acknowledged that not all services may be immediately available locally, and some services may need to be accessed virtually or regionally.

- To the extent possible, patients and families should be offered on-going and time-limited access to a wide a range of services including: public health; primary care; community services; social care and support; caregiver support – including respite care and bereavement support; specialized palliative care, including in-home palliative care teams, visiting and residential hospices, and specialist palliative care in hospitals; supportive housing or residential support, such as assisted living or long-term care homes, where needed; other disease, condition or procedure specific specialist inpatient and outpatient services; “hospice-friendly” acute and emergency care and complex continuing care, as required; and care coordination services focused on helping patients and families navigate their entire care journey. (See advice regarding evidence-based planning, capacity and resource allocation models for more details).

- To be effective, services must be clinically, culturally and socially appropriate and responsive to the diverse needs of patients and families to the extent possible – for example, by building a broad range capacities within specific services and teams as well as enabling teams to draw in knowledge and expertise from the patient’s faith-based, social, cultural and linguistic communities and personal support networks as appropriate.

- Health equity approaches should be integrated into all palliative and end-of-life services and supports. For example, programs should be reviewed each year using the MOHLTC Health Equity Impact Assessment template.

- Standards of care should be developed provincially, but within prescribed parameters, allow for flexible implementation at regional and local levels.

- It is recognized that some small communities – especially those in remote areas – may experience gaps in terms of the range of health infrastructure and services they have access to. This should be considered regionally in terms of on-going planning for health services through the LHIN. In addition, community capacity development has become an accepted practice approach to developing health services in diverse geographies such as rural and

\textsuperscript{32} See Kelley 2012 “Community Capacity Development in Palliative Care”. Another example of a successful interprofessional team approach is the award-winning Toronto Central Integrated Palliative Care Program, based on a CCAC partnership with Temmy Latner Centre for Palliative Care, and Mount Sinai Hospital.

\textsuperscript{33} DeMiglio, L (2012) “Sustaining Palliative Care Teams that Provide Home-Based Care in a Shared Care Model”

\textsuperscript{34} Seow, H. (2014). “Rethinking Palliative Care in the Community: A Change Guide”
remote communities, essentially 'building on what already exists' to creatively make use of existing assets to collectively improve the way care is organized and delivered to all citizens.

- With respect to First Nations communities specifically, the opportunity for federal and provincial governments and First Nations communities to work together to develop an appropriate response to meet the palliative and end-of-life care needs of patients within these communities is acknowledged.

- To enable better coordinated health care to complex patients approaching end-of-life, it is important to align provincial, regional and community palliative and end-of-life care strategies with the development of Ontario’s Health Links.

4. **Work within communities to normalize aging, death and loss**

- Community and social engagement are core components of sustainable systems. Collaborative community networks and processes help ensure the sustainable contribution of volunteer time, effort and resources which are necessary to the provision of palliative and end-of-life care. Currently, community action and grass roots efforts are primarily focused on the last few days and weeks of life such as through the development of residential hospice programs.

- Community perceived “norms” influence how patients and families may feel about end-of-life care. All communities can be supported to take collective responsibility for the end-of-life journey for the citizens within their geography and empowered to bring back the traditions and practices that helped keep people in their communities in the past.

- Citizens should experience end-of-life care as an expected and normal social and community event rather than primarily as a specialized care setting and set of treatments – consistent with a “health promoting palliative care” public health approach. While everyone’s experience of death and dying is unique, patient and families should understand that what they are experiencing and feeling is normal and be supported to calm anxiety and fear about the end stages of one’s life.

- There is significant opportunity to build capacity and provide earlier and more equitable access to care to the extent that we support defined communities in broadening their focus to include the entire end-of-life continuum and journey of its citizens. Behavioural and psychological research confirms the deep power of place to impact behaviour and normative culture. People and communities are empowered to normalize end-of-life care to the extent they feel a sense of control, influence over meaningful outcomes and have better ways to coordinate across boundaries.

- Community action through an organized and formally constituted community network or hub can help reframe and normalize aging, dying, and loss within that community as “life and living” for all its citizens to achieve the following outcomes:
  - It will support broader public access to information – by allowing for the contextually appropriate development within communities of highly visible, publicly accessible,

benign and welcoming “gathering places” where patients and families can easily turn to for information and advice.

- It will support earlier access and identification of patient needs within the community, and more equitable approaches to the delivery of care. Community-wide identification, inclusion and equitable delivery of services to ALL citizens approaching the end-of-life within their community will enable the community to take proactive responsibility for the community’s share of the 100,000 end of life patients who live within their neighbourhoods. This should empower communities to take on the specific responsibility of finding creative ways to support and attach the most highly vulnerable citizens within their 1% who are not able to self-manage, identify their own supportive networks, express their needs or have other unique service challenges.

- Where system gaps or barriers are identified within the community, this will allow community members to engage in collective problem solving and make “creative” use of available resources based on a health and community assets approach, that is respectful of the different legislative, regulatory and provincial policy frameworks under which different organizations operate.

- It will allow for the mobilization of common interests across health, social, non-profit and other sectors in the community around the normalization of care at the end-of-life. Persistent community action is sustained through a formal, virtual network organized as an organic, adaptive and evolving “integrated aging and end of life support ecosystem” that inspires collaboration with community leaders and leading organizations across various health, social service, non-profit and other sectors, as well as community partnerships with larger entities and institutions (hospitals, LTCHs, and Health Links).

- A small and short-term investment in facilitation is often necessary at the start of a community capacity building process. Facilitation can take various forms however it will not dictate the actions - flexibility is important to allow the community to evolve around their existing resources and priorities.

- This will support OHTAC and OMA priorities regarding public engagement in the normalization and de-medicalization of death and dying. While the province and LHINs enable the development of core health infrastructure and influence action through its policy, planning and funding levers, they lack tacit knowledge of community assets, culture and relationships that are needed to improve care and the quality of life of dying residents.

- The government has committed to develop a policy on community hubs, reflecting the perspective of health and wellness. It is acknowledged that there is only one community, and efforts to advance a variety of population specific or specially focused hubs need to be practical and should not become fragmented within communities. For example, the focus on end-of-life action may be one of several focuses within a formally constituted community hub or network.
5. **Strengthen and optimize residential and hospital inpatient capacity for people facing imminent death**

**Optimizing Residential Hospices**

*Need for updated funding, planning, policy and service frameworks*

- Residential and voluntary hospice services will be best utilized and optimized to the extent that the funding, planning, policy and service frameworks under which they operate is updated and structured within an organized, integrated, programmatic, community-based palliative and end of life system of care, including the establishment of formal accountability and funding relationships with their LHINs, based on the models outlined in this paper.
- Ontario recognizes that palliative and end-of-life care encompasses a spectrum of activities beyond administering medicine and has made regulatory amendments to clarify the scope of the property tax exemption for non-profit hospices providing end-of-life care.

**Strengthening community service orientation**

- It is impractical to think about residential and voluntary hospice services as health care settings or services outside of their communities. Many have deep, long and lasting roots in the communities they serve. For the most part, they already have high public visibility, credibility and are fixed in the public’s imagination as a necessary, helpful, and compassionate community resource. They have been built through persistent community activism and fundraising. Many communities have demonstrated an extraordinary ability to mobilize volunteers and engage their communities in end of life issues. While not the only resource, they are a key asset that can be utilized and optimized to strengthen Ontario’s end-of-life continuum of care.
- There is an expectation that all hospice services will maintain a strong community service orientation at a governance, staff and facility level; will provide or contribute to community-focused services and not just facility services; and will develop strong collaborative practices that cross primary and community care as well as hospital and LTCH settings.
- Acknowledging the need to increase the knowledge about hospice palliative care generally and residential hospice care specifically and ensure the full spectrum of services are available to, and known by, all Ontarians, there is an expectation that hospices will be part of community-wide efforts to establish well known and easily accessible public spaces for the public to have all of their questions and concerns about death, dying and loss answered.

**Access Considerations**

- In all LHINs, access to residential hospice beds as well as wait list management should be planned and coordinated through a consistent, standardized, regionally-based care coordination process and model to the extent possible. The access point for coordination of care should reflect the entire journey of care and leverage existing community-based models.
  - While patients can be referred to a residential hospice through various means, including a health care professional, institution, Health Link or by contacting a
residential hospice or CCAC directly, within each LHIN, the home and community and hospice sector will establish a transparent and publicly communicated process for collaborative, streamlined intake. Home and community agencies will ensure timely and coordinated access, intake and assessment processes as set out in the Policy Guideline for CCAC and CSS Collaborative Home and Community-Based Care Coordination, 2014 (including the specification of responsive service standards specific to patients with palliative and end of life care needs).

- This paper outlines a series of actions to ensure that patients approaching their last year of life are better identified prospectively, and personalized team and journey-based care coordination processes are continuous and available more broadly. For most patients in the future therefore, access and admission to a residential hospice should not be a surprise, but will be planned for and organized in advance, informed by their existing needs assessment, preferences and overall care plan.
- That being said, structured but flexible local processes should be established that would allow a patient to move into a residential hospice quickly when urgent circumstances arise at times when CCAC care coordinators may not be immediately available and suitable arrangements cannot be made in advance (e.g. a provision for admission directly to a residential hospice should continue to be included in LHIN or CCAC accountability contracts with residential hospices).

- Arrangements should be made to ensure all patients in all communities have equitable access to residential hospice beds where end of life is imminent.
  - Needed bed capacity and appropriate models should be considered through a LHIN regional planning process, based on approved planning models and benchmarked capacity relative to community population levels and needs. For example, the proposed services and resources planning model for patients approaching end of life suggests as an initial planning guide, that about 12 to 15% of the 1% of patients facing approaching end-of-life within the community may need access to residential inpatient care setting during their last weeks of life (i.e. cannot or prefer not to be cared for at home), but do not need hospital level care.
  - Equity of access across different population and communities within the region is a key consideration. Specifically, whether or not a formal free-standing hospice has been approved and is in operation, within each community, the LHIN should establish procedures and processes for community residents to access needed inpatient “residential hospice” programs or their equivalent relative to the community’s population base, within a reasonably close distance to the patient’s home. Where necessary, interim arrangements may be considered, including examining options for re-profiling existing bed capacity in hospitals, LTCHs or other appropriate settings for this purpose or securing access to regional resources located in reasonable proximity to the patient’s community.
  - Residential hospices should have access to the information and supports they need to customize their care processes to meet the specialized needs of unique and diverse populations – such as children, people with developmental challenges, mental health issues, behavioural or cognitive impairment, having language barriers, or needing specialized medication – in order to appropriately meet the needs of the
communities they serve, or, alternatively, such patients must be able to conveniently access specialized regional resources located in reasonable proximity to the patient’s community, in accordance with the priorities set out within the LHIN regional plan.

- LHIN planning considerations and decisions will be based on optimizing services and resources to meet population needs while maximizing efficiency, existing capacity and best use of resources. Shared back office functions may also be considered across program areas.

**Flexibility in models within an appropriate standards framework**

- No one model or approach will be best for every purpose. While models should conform at a principles level, there is room for local variation and flexibility to accommodate diversity.

- Different models need to be considered to meet the needs of small communities:
  - The RHWG is not recommending a minimum size requirement for residential hospices. There is recognition of the need for more flexible models in smaller communities which do not have a population or service base to make the development of a 10 bed residential hospice model feasible or affordable. It is also acknowledged that many small communities are evolving effective and appropriate models that include more flexible dispersed, cluster or co-location arrangements and broader use of non-professional resources with access to professional services as needed. It is important that these new approaches be rigorously evaluated and shared to both inform system learning and to optimize program design and implementation.
  - Any residential hospice, regardless of care setting or size, must meet all applicable residential hospice standards (see section below), and must operate a program which is financially sustainable relative to the community and population it serves.
  - Given the expected role of the residential hospice, its dedicated focus, its community profile, and its attachment to the end-of-life community hub, co-location of a residential hospice in institutional settings is not preferred but is not precluded.

- All residential hospice should meet prescribed, updated standards and best practices:
  - The Hospice Palliative Care Ontario accreditation framework should be broadened to include residential hospices.
  - The current residential hospice standards, once the term “stand alone” is removed, may also be applicable to residential hospices operating within other care settings.
  - Recognizing that the provision of meeting a 24/7 nursing standard is challenging for some existing or evolving models in smaller communities, HPCO is currently working on language to clarify circumstances where an exception to this standard may be permitted. Formalizing this exception and adopting it into an appropriate standards framework is critical.

**Advancement of hospice “programs of excellence”**

- Each residential hospice (and any setting where inpatient hospice beds are offered) should be part of a formal program of excellence in palliative and end of life care, including engaging in community capacity-building (e.g. leadership and subject matter expertise),
shared learning (e.g. education, training, certifications, team building, etc) knowledge management and exchange (e.g. facilitating the collection of standards, practices, knowledge repositories, and outcome metrics), knowledge translation, public communication, building strong research and academic partnerships, and engaging in processes for continuous improvement to best ensure high quality care to patients and families that meets their needs.

- As part of any program of excellence, specific consideration should be given to practical, scalable solutions that better reflect the expectation of collaborative, shared practices between inpatient and community hospice services and between hospice services and primary level care services.
- Residential hospices should have formal collaborative partnerships with hospitals (as well as community-based services) in their communities, recognizing that residential hospices are an important resource to hospitals who may need to move patients from acute care or alternative level of care beds into settings more appropriate to their needs.

Supporting Volunteer Capacity and Engaging Families

- Hospice volunteers are an important asset in providing assistive care in both residential hospice and in-home settings.
  - All volunteers must complete the HPCO 30 hour accredited hospice volunteer training course and additional hands-on training.
- Family and friends are encouraged to participate in the care of their loved one to the degree they wish. Accommodations are usually available for family members wishing to stay overnight at the hospice.

Optimizing Inpatient Care in Hospitals

- From time to time, patients approaching end-of-life will also need access to 24/7 highly specialized, tertiary, acute and/or complex continuing care that is provided within a healthcare facility. Care in these settings should be appropriate for patients with palliative and end-of-life care needs and be offered where possible in environment that is welcoming to families. Care should be delivered by an interprofessional team, with access to appropriate palliative care expertise where necessary.
- In regular hospital settings, time-limited, episodic care is provided, although some patients approaching end-of-life may require hospital level care for extended periods or may die in hospital.
- Some patients will require specialized hospital-level end-of-life care. Depending on economies of scale, these services may be provided in a designated palliative unit, designated palliative beds, specialized clinic or centre. Alternatively, patients might receive enhanced care through a mobile specialized end-of-life team for patients in general beds, or through a mixed model (for example “swing bed model” where critical care staff provide end of life care in the CCU or any other unit or in partnership with hospice providers).
- Similar to residential hospices, needed bed capacity and appropriate models should be considered through a LHIN regional planning process, based on approved planning models and benchmarked capacity relative to community population levels and needs. For example, the proposed services and resources planning model for patients approaching end
of life suggests as an initial planning guide, that about 15% of the 1% of patients approaching end-of-life within the community may need access to specialized hospital-level palliative care inpatient beds during their last days of life.

- In the future, through the Declaration priorities and implementation plans, consideration should be given to the development of “hospice friendly” hospital standards.

6. **Ensure strong provincial and regional oversight and accountability**

**Regional and Provincial Oversight**

- This advice is intended to fit within the overarching provincial and regional level governance mechanisms being established in Ontario to implement the Declaration of Partnership.
- The advice outlined in this report will complement and support efforts to develop more effective formal integrated programs and teams originating through provincial initiatives, regional programs, and/or individual organizations. Specifically, it is expected that the LHIN regional program or network will play a critical role in reviewing options and making recommendations to their LHINs on resource and capacity planning and building integrated systems both regionally and locally.
- At a regional level, centralized planning and oversight through each LHIN is critical to building appropriate health system infrastructure and capacity development to reduce gaps, strengthening service integration, creating system efficiencies and optimizing the use of scare resources, and ensuring regional and province-wide learning and uptake of leading practices.
- Like the wide range of separate health programs located within its geography, each local end-of-life community hub within a region will be accountable to its LHIN. Local hubs will work together to contribute to strong regional systems, within the scope, parameters and oversight mechanisms established by the LHIN through its regional palliative care program or network.

**Shift to outcome-focused delivery and measurement**

- Models, delivery methods and processes should be principle-based but flexible and allow for community customization. Outcome measurement on the other hand should be standardized, incorporating important person-centred and community outcomes, and regularly and transparently reported.
- Systems should be established to enable patient-relevant outcomes to be aggregated and reported at all levels (patient, team, community, region and province) and to track population benchmarked outcomes across care settings (with opportunity to translate these over time into shared accountability expectations)
- Performance reporting systems should be built to provide a comprehensive way to capture and build awareness of profiles and outcomes by groups of patients with similar need, as well as measure how health status, utilization, costs and experience for defined populations differ across regions and over time. In particular, this reporting system should permit:
  o Each patient’s outcomes and true costs to be measured and reported by subgroup.
  o Change in defined population shared outcomes over time for each subgroup to be regularly monitored.
o Change in outcome improvement over time relative to cost to be calculated at multiple levels.

- Specifically, outcome reports segmenting patients based on level of need (using standardized assessment tools) will create a more comprehensive picture of equity across the system – that is, our ability to ensure equitable access to equitable levels of service for similar patients.

- “Place of death may be considered a robust indicator of how societies broadly approach death and dying and how they have accordingly organized their end-of-life care”. While only a small part of the patient and family end-of-life journey, measurement of place of death is critical and should be an important focus of improvement efforts. This includes consideration of approved population benchmarked standards that are consistent with patient need and preference evidence.

- Teams and hubs should work towards province-wide standardized measures and data processes. Metrics should be used to cascade patient and front-line performance to system outcomes. The domains for performance measurement include:
  o Person- and family-centred.
  o Equitable and access.
  o High quality care and value for money.
  o Integration of services and transitions of care.

- There is a need to leverage existing funding reform opportunities and consider incentives and disincentives driving system behavior that are currently in contrast to an “optimized” model, recognizing that creating the “right” set of incentives is a tricky business.
  o Start by tracking utilization and costs relative to value and population outcomes within and across care settings, as well as in the context of broad community-level patterns of care (with the opportunity to standardize funding corridors across care settings based on group or population level of need over time).
  o Understand patient/family financial burden related to care setting (with opportunity to equalize over time).
  o Examine how well existing payment incentives are achieving their intended purpose, and whether there are unintended consequences undermining value which need to be addressed.

- To ensure that each patient and family receives high quality care in every care setting within the end of life continuum, Ontario’s approach to the delivery of care to patients with palliative and end-of-life care needs should promote population consistency while allowing for individual flexibility and allow for “customized standardization”.

- At a regional or provincial level, it is important to establish clarity around issues that cross boundaries, such as privacy, risk management, shared accountability, joint and severable liability etc. so each community, organization and team doesn’t individually have to repeat this work and potentially come to divergent viewpoints.
7. **Use technology as an accelerator for connected, integrated systems**

- Continued examination and experimentation with new technologies is considered essential to extending the reach of programs (e.g. e-shift in palliative home care); access to specialist care (e.g. e-consult; use of OTN virtual visits) extending the reach and breadth of support to families (Skype in First Nations communities); to increase safety and early interventions at home (e.g. telehomecare); and to better manage information, releasing provider time to care (e.g. tablet technology program).

- New processes should be developed for real-time sharing of information across boundaries. At a regional level, through small start-up investments, the use of bridge technology should be considered between residential hospice systems, community and home care systems, and medical systems – for example, OSCAR platform upgrades in HNHB LHIN to enable connectivity to multiple EMRs, Clinical Connects (home care) and Infoanywhere (hospices) to enable a paperless chart to follow patients across care settings. It is however noted that there is a range of technology solutions being used within the sector and standardized use of technology must ensure capacity for the collection of reliable data, and be able to be connected with province-wide integrated platforms such as the Integrated Assessment Record.

- Use of citizen-driven technology that follows the patient throughout their journey should be considered.

- It is noted that for some communities, especially in northern and remote areas, sufficient internet connectivity and broadband access must first be established.

- It is further noted that First Nations communities could benefit but currently do not have access to Ontario Technology Network (OTN) services – jurisdictions should work together to minimize such barriers.
ADVICE REGARDING EVIDENCE-BASED PLANNING, CAPACITY AND RESOURCE ALLOCATION MODELS

The research and evidence examined through this process also helps inform the development of effective planning and measurement tools to ensure needs-based resource allocation and optimal utilization. Such tools should be applicable to and shed light on the totality of care needs for the whole end-of-life population - specifically, equitable planning and measurement tools need to take into account all known trajectories of death.

Fig. A: Terminal Trajectory of Death
- Cancer – 29% of all deaths

Fig. B: Organ System Failure Trajectory of Death
- Organ System Failure - 27% of all deaths

Fig. C: Frailty and Dementia Trajectory of Death
- Frailty and Dementia – 27% of all deaths

Fig. D: Sudden or Unknown Trajectory of Death
- Sudden deaths – 6% and unknown deaths 11% of all deaths

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I. Health Service Utilization: End-of-Life Service And Resource Planning

A. End-of-life Stage of a Palliative Journey for Community-Dwelling Patients

*Community ecosystem model: organizing a system of integrated services across the patient journey as a flexible space/time continuum with continuous, seamless and time sensitive care and support*

*Integrated Community Service Model (including episodic care)*

- Applicable to patients residing in the community – targeted to the approximately 80,000 Ontarians within their last year of life. “Community” in this model is used in the broadest sense of where people live and what they consider community. Community services include but are not limited to CCAC and community support services but also encompass other health services, social, municipal, virtual, volunteer, and personal supports.
- Possible in-home settings include the person’s home, retirement home, supportive or public housing, and other forms of community dwellings – including patients who may require intermittent intensive inpatient care from time to time.
• Under this model, patients and families should be able to receive 24/7 care and support at home through a personalized mix of self, family, informal, volunteer and professional caregivers, including integrated community, primary care, residential, episodic and other care spanning entire frailty/CDM trajectory.
• By leveraging existing health system infrastructure and building community capacity over time, patients and families can be offered on-going or time-limited access to a wide range of services locally, regionally or virtually including:
  o **Public health, primary and community health care**: Community physician/NPs, community interprofessional teams, nursing, PSW, therapy, supplies and equipment, pharmacy, community support, public health, and navigation support in accessing other needed services – provided at home or in a location that is appropriate to the person’s needs and mobility limitations.
  o **Caregiver support**: Integrated caregiver support including training, education and information, one number to call coordination support and 24/7 crisis response, day hospice programs, access to short-term respite care that may be provided in a range of settings, and bereavement support.
  o **Specialized community-based palliative care**: Coordinated access to appropriate community-based hospice services including volunteer visiting, specialized palliative homecare, palliative interprofessional in-home teams, professional outreach programs for consultation/mentorship, education and training. Community-based services are appropriately linked with residential hospice beds and hospital services – including access to specialized tertiary palliative care beds.
  o **Specialist and episodic outpatient, inpatient and emergency care**: Disease or condition-related inpatient and outpatient specialist care; coordinated acuity-related access to tertiary or specialized, intensive support to manage and stabilize acute exacerbations or for intensive restorative care; appropriate emergency services/response – including appropriately identifying patients in terms of unmet palliative care needs and linking them back to appropriate community supports.
  o **Residential care**: Range of supported housing and assisted living environments for people who need longer-term residential support and cannot be cared for at home.
  o **Social care and support**: Unique to the community but would include social services, municipal services, NGOs, public housing etc.
  o **Personal, informal and social network support**: Unique to the person and family, recognizing that this capacity might be minimal for some patients and families.
  o **Care coordination**: Complex care coordination model focused on the patient journey, not simply discrete episodes of care and transitions. Streamlined navigation and coordination support is based on patient and family preferences and bridges medical coordination, home and community coordination, and self-management.
• Processes for early identification and outreach are embedded as well as virtual, proactive, continuous, integrated, team-based care (i.e. the Declaration model of care).
• Intensity and range of services is decided with the patient’s informed consent and is informed by a standardized comprehensive needs assessment. Intensity and range of services increases with increased levels of patient and family complexity. Access to formal
health services is typically determined based on clinical judgment in accordance with specific eligibility and program requirements.

- Each separate component with the community ecosystem will develop relationships with other components in order to achieve their objective of person-centred care.
- Services will be organized around specific patient and family preferences and goals, clinically, culturally and socially appropriate, and responsive to the diverse needs of patients and families to the extent possible – for example, by building a broad range capacities within specific services and teams as well as enabling teams to draw in knowledge and expertise from the patient’s faith-based, social, cultural and linguistic communities and personal support networks as appropriate.
- Within this “integrated community ecosystem”, a mix of governance, learning and accountability mechanisms ensures:
  - Service delivery is based on evidence in order to improve quality and outcomes for patients and families;
  - Service provider and population outcomes are transparent;
  - Payment is based on evidence to reinforce quality and result in efficient use of resources (e.g. service guidelines are used to provide guidance for decisions regarding care and service allocation, and increase transparency to the public about service level expectations);
  - Quality measures and feedback are embedded to drive continuous quality improvement and accountability for outcomes.
- NOTE: in addition, LTCHs should also be capable of providing appropriate “hospice-friendly” care for their residents at imminent end of life who do not require hospital level care – see separate LTCH model below.

**Residential hospice**

- A residential hospice provides a home-like environment where adults and children with life-limiting illnesses can receive end-of-life services where death is imminent and a home death is not possible or preferred but hospital level care is not required (estimated at about 10,000 to 12,000 Ontarians annually within the last few weeks and days of life).
- Patients receive 24/7 care delivered by an interprofessional team with palliative care expertise.
- Services are anchored in and part of the community. Families are welcomed and play an important role as part of the care team but are not responsible for the patient’s care. Families participate to the degree they wish to.
- May be a healthcare facility or registered charity.
- May be located in a free-standing building or co-located in another healthcare setting.
- Within the parameters of the overarching LHIN regional palliative care plan, each community should have a plan for population benchmarked residential hospice bed capacity – see capacity benchmarks for residential hospices noted below.
- Strong, seamless virtual or formal integration between residential hospice services and community hospice services is expected.
- Each community should have a regionally approved plan for population benchmarked residential hospice bed capacity – see capacity benchmarks noted below.
• Once residential hospices are fully integrated within an integrated system of care, depending on LHIN funding and planning decisions and where applicable legislative and regulatory requirements are met, the organization that operates a residential hospice may also be approved to provide other important hospice-friendly community-based services such as respite support, pain and symptom management, day programs, specialized palliative outreach or in-home support teams, and even assisted living or housing supports targeted to people with advanced, serious illness.

Hospital-Based Acute, Specialized and Complex Continuing Care
• For patients approaching end-of-life requiring hospital-level acute care, specialized palliative care, or complex continuing care – includes patients facing imminent death or experiencing a sudden, catastrophic event requiring hospital level care (estimated at about 25,000 Ontarians annually); those who died in hospital where death was not expected; and acute care episodes experienced by palliative patients which did not result in death.
• Patients receive 24/7 care delivered by an interprofessional team with access to appropriate palliative care expertise when needed provided in a “hospice-friendly” environment, regardless of which program or unit within the hospital they are admitted to.
• Each region should have a plan for population benchmarked tertiary level palliative care bed capacity – see capacity benchmarks for hospital-based beds noted below.
• There is an expectation that hospitals will have strong connections with the community to facilitate appropriate admissions and discharges (for non-terminal episodes) to ensure patients receive the right level of care at the right time in the right place.
B. End-of-life Stage of a Palliative Journey for LTCH-Dwelling Patients

Integrated LTCH Service Model

- All residents within a LTCH should have access to a modified hospice-friendly community continuum as described above, including residential and preventative care that is integrated with hospice services and on-going acuity-related access to specialized, intensive support to manage acute exacerbations, restorative care and stabilization.

- Capacity building approaches along with appropriate education, training and mentorship should be available to LTCH staff and volunteers to increase their comfort and familiarity with the provision of “hospice-friendly” generalist care.

- Residents facing imminent death will receive 24/7 end-of-life services and supports delivered by an interprofessional team with access to appropriate palliative care expertise (estimated at about 20,000 Ontarians annually).

- Families are welcomed as part of the care team and supported to deal with their own issues of loss and bereavement but are not responsible for the patient’s care.

- Depending on LHIN priorities in accordance with their regional plan, short-stay programs within a LTCH could admit community-dwelling patients approaching end-of-life who require respite care or hospice-friendly support equivalent to a residential hospice.
C. Model for Integrated Continuum of Care Settings (based on needs and preferences)

Population Planning Model: Capacity Benchmarks

**Key: Relative Population Scale**

<table>
<thead>
<tr>
<th>Level</th>
<th>1 (Lowest Needs)</th>
<th>2 (Moderate Needs)</th>
<th>3 (Highest Needs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>63% (63,000)</td>
<td>12% (12,000)</td>
<td>15% (15,000)</td>
</tr>
<tr>
<td>Beds</td>
<td>n/a</td>
<td>n/a</td>
<td>10% (10,000)</td>
</tr>
<tr>
<td>1/100,000</td>
<td>n/a</td>
<td>n/a</td>
<td>1/10,000</td>
</tr>
</tbody>
</table>

**Benchmarked Bed Ratios and LOS assumptions**

**Residential Hospice Capacity – Patients Facing Imminent Death**

A benchmarked population-based bed ratio of between 5.1 to 6.8 beds/100,000 per community is recommended. This ratio corridor is consistent with international best practices. \(^{37}\)

**Supporting Analysis:** If about 12,000 Ontarians require care in a residential hospice within any given year (adjusted based on 2012 population levels) with an average length of stay (LOS) ranging from three weeks to one month:

- For 3 week LOS: 12,000/17.3 (i.e. the number of three week periods in a year) = 693.6 beds required at any given time. The population of Ontario is 13.51 million (2012). When compared against the rate of the population of Ontario, 5.1 beds would be required/100,000 population.

\(^{37}\) For detailed comparators, see inter-jurisdictional analysis in the RHWG Environmental Scan (November 2014)
For 4 week LOS: 12,000/13 = 923.1 beds required at any given time. When compared against the rate of the population of Ontario, 6.8 beds would be required/100,000 population.

LHINs should use this model as a guideline for establishing appropriate population-based capacity and resources, understanding that a degree of flexibility and fluidity needs to be built into on-going planning assumptions and some regional variations are to be expected at least initially. This range is suggested in order to accommodate:

- While a significant change in the target population served by residential hospices is not contemplated, the possibility that residential hospices will serve greater numbers of patients with frailty and organ failure who are clearly close to death over time.
- The possibility that residential hospices will serve a greater proportion of socioeconomically deprived patients who are relatively less acute but need care for longer periods of time because they lack an appropriate home environment and people to care for them.
- The varying capacity, availability, maturity, and success of integrated community-based systems offering robust in-home services and supports that help prevent or delay access to residential hospice or hospital care where this is not the patient and family preference.
- The varying availability and distance required to access regional hospital-based palliative care beds.
- Future demographic trends and changes in the relative distribution of deaths along the 4 death trajectories (that is, the continuing trend towards a decline in cancer and organ failure deaths and relative increase in frailty related deaths).
- There may also be minor variability in some communities from the benchmark depending on factors such as the relative proportion of older residents within the community compared to provincial averages, and the multi-cultural makeup of the community and how their values and norms regarding various dimensions of end of life care might influence different utilization patterns.

NOTE: While inpatient hospice care at primary and secondary levels is preferred within dedicated residential hospice settings because of the unique focus and specialized expertise available, consideration of other locations is not precluded. Examples of different options might include developing primary and secondary hospice capacity within a hospital, residential or short-stay LTCH program setting, providing any such programs operate within the approved residential hospice standards and meet all applicable quality of care requirements.
See appendix for additional information on the breakdown of current and planned residential hospice beds by region.

NOTE: It is noted that residential hospice bed planning in Ontario, 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 this report.
**Tertiary Hospital-Based Palliative Care – Patients Facing Imminent Death**

About 15% of the palliative care population may have complex needs requiring intensive services of a hospital or hospital-based palliative care unit.\(^{38}\) Based on this estimate, assuming an average one week length of stay in hospital prior to death, the benchmarked population-based ratio of tertiary/specialized hospital level beds would be 2 additional beds in hospital settings/100,000 population over and above community-focused residential hospice beds.

**Tertiary Hospital-Based Palliative Care – Other Palliative Patient**

*Respite Care, Short-Stay Convalescent, Assistive Living – Patients Approaching their Last Year*

Additional bed capacity may be required throughout the patient’s end-of-life journey, not just in the last weeks and days of life. As noted in the integrated community service model discussed above, many patients with serious, advanced illness, whether or not they are designated as palliative, will need access from time to time to appropriate respite care, short-stay beds and inpatient and outpatient acute and episodic care services. Options for enhanced supportive housing and assistive living may also be required, on both a short and longer-term basis, especially for patients whose disease trajectory may be unpredictable, prognosis of death uncertain, and who are not able to be cared for appropriately at home, for whatever reason. These resources are in addition to the population-based benchmarks noted above. Benchmarked capacity for these services and resources remains to be determined.

In the community, depending on the LHIN regional plan and community capacity and priorities, consideration may be given to co-locating respite care with residential hospice programs or in long-term care homes. In inpatient settings, depending on the LHIN regional plan, beds located within a palliative care unit may be targeted to serve palliative patients who are not yet facing imminent death, but are better and more cost-effectively served within a specialized palliative care unit rather than within a general acute care bed.

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\(^{38}\) National Council for Hospice and Specialist Palliative Care Services 1999
II. Team-Based Care and Coordination Models

Reinventing “Teams”: Shifting to Integrated and Flexible Person-Centred Delivery
(Putting Patients and Families at the Centre; Shifting from setting-based care to integrated Circles of Care)

Health System/Program View of a “Palliative Care Team” 39

(Team as a set of core resources and standardized care processes – may be either virtual or program-based – serves a roster of patients with limited time for each)

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39 Seow, H. (2014). Rethinking Palliative Care in the Community
As per the Declaration Vision, the expectation is that all individuals with advanced chronic or terminal disease(s) or frailty will receive care that is proactive, holistic, person and family-focused, centering on quality of life and symptom management issues, and delivered by an integrated interprofessional team in a coordinated, continually-updated care plan, regardless of individual health care setting. The construct of “team” in the context of this vision is multi-layered: while it will be viewed differently from different levels and over different timeframes, each of these layers must operate synergistically and in a connected, cohesive and organic way.

**Patient’s View of their “Personalized Team”**

(TEAM as a personal and unique combination of the TOTAL formal and informal resources in their environment that help whenever needed)

This view of a patient’s “personalized team” is consistent with a behavioral model of health services utilization which suggests interactions between the person’s external environment and patient characteristics determine healthcare use and ultimately, the health outcomes the person experiences. Therefore, different strategies must be targeted at both the external environment (for example, the availability of an effective palliative care program/community-based team) as well as patient characteristics, including support to better leveraging their own and community social networks in order to optimize outcomes for both the individual and the system.
Community View of Range of Assets Supporting Personalized Teams

(Team as a combination of integrated services, providers and teams across entities of care relevant to the patient; single historically grown institutions/sectors can no longer be seen as the default)

Time series view of the necessary fluidity of teams and how composition changes over time
This model promotes early identification and is fluid and integrates chronic disease management and palliative care from diagnosis until death and through to bereavement. The expectation is that the core team and careplan is continuous - once you are known in the system from diagnosis, you should never become unknown.

**Stages of growing an end of life program through a model for capacity development**
Effective teams have deep roots within and grow from their communities – they are developed through an organized and on-going process of community engagement, capacity-building, and empowerment.
Great teams don’t just happen – they are created, organized and managed.

“Every organized human activity—from the making of pots to placing man on the moon—gives rise to two fundamental and opposing requirements: the division of labour into various tasks to be performed, and the coordination of these tasks to accomplish the activity. The structure of a [team] can be defined simply as the sum total of ways in which it divides labour into distinct tasks and then achieves coordination among them.” (Minzberg, 1971)

“Team”- related activities at each of the patient, provider and community levels also need to be coordinated. Especially for patients with complex care needs, care coordination functions will simultaneously and interactively occur through patient/family self-directed activities and functions, home and community care provider activities and functions, and broader system or network activities and functions. Each of these complimentary processes needs to be understood and aligned to enhance patient and family experience. This requires a high degree of communication, information exchange and coordination to ensure each process adds value to the patient and is not duplicative. The following provides a conceptual model for simultaneous and complementary individual (i.e. self-management), sector (i.e. Home and Community Care Coordination) and system care coordination processes (e.g. Health Links):
III. Complexity Model and Best Evidence Delivery Characteristics

Complexity and level of need should be the driver of services at end of life, not prognosis or survival estimates. Complexity is also the driver of the delivery model for care in the long-term. Complexity must be understood in both absolute and relative terms.

**Population complexity and needs-based care model**

- **All** patients approaching the end of their lives are complex, given the extent to which they are medically compromised (and the associated probability that they will experience needs which are severe, unstable, urgent, or terminal) as well as the significant personal, spiritual and psychosocial issues they face (often requiring a broad scope of services to address).
- That being said, patient- and family-level complexity must also be seen as a “nested” or relative concept – that is, even within this group of complex patients, there are levels and degrees of complexity which patients can cycle through – supportive services should focus on managing and mitigating the risks associated with relatively greater levels of complexity and helping maintain and support patients as long as possible at primary and community levels.
Evolving Understanding of Morbidity and Complexity

**Comorbidity**: presence of additional diseases in relation to an index disease in one individual.

**Multimorbidity**: presence of multiple diseases in one individual.

**Morbidity burden**: overall impact of the different diseases in an individual taking into account their severity.

**Patient’s complexity**: overall impact of the different diseases in an individual taking into account their severity and other health-related attributes.

Complexity as the driver of the care model: Distinguishing Characteristics of “Leading Practice” Care to Complex and Long Term Populations

<table>
<thead>
<tr>
<th>Biomedical model</th>
<th>Bio-psychosocial model</th>
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<tbody>
<tr>
<td><strong>Disease Management</strong>&lt;br&gt;Prevention, cure or relief of symptoms</td>
<td><strong>Long-Term Community Management</strong>&lt;br&gt;Integrated, personalized care</td>
</tr>
<tr>
<td><strong>Population characteristics:</strong>&lt;br&gt;Disease +&lt;br&gt;Comorbidity +&lt;br&gt;Multi-morbidity</td>
<td><strong>Population characteristics:</strong>&lt;br&gt;Disease + High morbidity burden (advanced, late-stage disease; frailty) interacting with non-health attributes (disabilities, behaviour, social &amp; environmental vulnerability, social determinants of health)</td>
</tr>
<tr>
<td><strong>Screening</strong> based on biomedical microvascular relative risk factors</td>
<td><strong>Screening</strong> on a range of factors triggering more comprehensive assessment</td>
</tr>
<tr>
<td><strong>Disease specific “evidence-based” guidelines and carepaths (RCT -based)</strong></td>
<td><strong>Population-based integrated services and shared outcomes</strong> (with rigorous testing of impact) combined with use of personalized, continuous, patient level careplans</td>
</tr>
<tr>
<td><strong>Coordinated care:</strong> horizontal &amp; vertical substitution; management of transitions; patient self-care</td>
<td><strong>Integrated care:</strong> Collaborative, continuous care involving patients &amp; their informal supports, medical, mental health, social and community sectors within engaged communities</td>
</tr>
<tr>
<td><strong>Program-based case management / care planning (time-limited and episodic)</strong></td>
<td><strong>Journey-based care coordination</strong> within engaged communities</td>
</tr>
<tr>
<td><strong>Disease prevention</strong></td>
<td><strong>Health promotion, preventative and restorative care</strong> focusing on perceived quality of life</td>
</tr>
<tr>
<td>Evaluation of surrogate clinical measures</td>
<td><strong>Patient-reported outcomes</strong>, health status, and cost tracking with IT-enabled data sharing, real-time risk monitoring and decision-making aids</td>
</tr>
<tr>
<td><strong>Informed consent</strong> (power and information imbalance between patients and providers)</td>
<td><strong>Shared information and decision-making</strong> with patients</td>
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GETTING STARTED

As Working Group members representing the ministry, LHINs, home care, palliative care, and residential hospice care sectors, we share the belief that the actions outlined in this document will significantly strengthen Ontario’s end of life continuum of care for Ontario residents and their families, by improving person, caregiver and provider experience, enhancing quality of life prior to death, alleviating complex bereavement after death, reducing avoidable emergency visits and hospitalizations, and better supporting people to die in their location and circumstances of choice.

Building on the Declaration of Partnership, this report presents a vision for the strong and integrated system of end of life care in Ontario that we aspire to create. Acknowledging that the evolution to a more integrated population-based system is complex, we understand that improvements will be iterative. However, as a partnership we are committed individually and
collectively to moving forward with action that puts us on the path to achieving our desired future state.

This report proposes a journey that all partners and communities should undertake – not a sequential exercise. Many of the necessary elements already exist in the many communities – leaders and decision makers should build on existing capacity by continuously taking small steps forward to improve the quality and value of the existing models and practices, to address gaps, and to build stronger integrated systems of care. Because of different starting points, the journey may look different in different communities.

Each partner can choose to use this report to help inform change within his or her realm of influence and control. Where the action is within our own respective sphere of control to implement, we commit to implement this action as soon as practical. We further commit to share knowledge and influence our colleagues, organizations and networks to take similar actions. Where taking action is dependent on other partners or decision-makers, we commit to continuing to collaborate and engage in dialogue with them to advocate for change to improve the lives of Ontarians approaching end-of-life. Specifically:

- Grassroots community planners and leaders may consider this advice as they move to develop hospice “programs of excellence” and as they work to improve upon their existing models and programs, including better integration and communication across care settings and providers.
- LHINs may consider this advice as they: build or enhance their regional palliative care programs; continue to implement their 3 year regional plans; engage in planning processes to ensure equitable access to appropriate capacity and models across all Ontario populations and geographies; and develop strategies to best align existing and new resources and capacity to address highest priority needs and gaps.
- The Ministry of Health and Long-Term Care will consider this advice to help inform policy decisions and system-wide planning.

Starting immediately, all partners should take whatever steps are necessary to ensure foundational pillars are in place in all communities, in accordance with the following system design framework
A System Design Framework - A Primer on Possible Components Of Ontario’s Hospice Palliative Care System
(September 2010, prepared by Ontario’s Provincial End of Life Care Network and endorsed by Quality Hospice Palliative Care Coalition of Ontario Steering Committee)

Future

Research and Development: Continued research and program evaluation

Policy development: While outside the scope of this Working Group, it is recommended that additional policy work is undertaken regarding the availability of consistent funding, accountability and performance across care settings.

This is a “living” document that may be maintained, reviewed and updated as new evidence and information becomes available. As such, this document is a reflection of its time and will continue to become increasingly comprehensive as further input is received, discussed and canvassed for greatest system consensus.
## APPENDIX: Supporting Research and Analysis

### A. Place of death gap and unmet need

<table>
<thead>
<tr>
<th>Current State Synopsis – Place of Death and Unmet Need</th>
<th>Leading Practices – Synopsis of Research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>29,000 EOL cancer deaths</strong></td>
<td>Access to on-going community care throughout the palliative journey:</td>
</tr>
<tr>
<td>The majority of patients with advanced cancer do seem to be identified for palliative care services</td>
<td></td>
</tr>
<tr>
<td>• 75% of palliative home and community patients have cancer (15,000); 85% of residential hospice users have cancer with mid to higher acuity (2,000); regional cancer centres provide outpatient palliative care services exclusively to cancer patients</td>
<td></td>
</tr>
<tr>
<td>Despite this, there remains some evidence of unmet need</td>
<td></td>
</tr>
<tr>
<td>• 1,000 patients over one year who died on a waiting list prior to admission to a hospice</td>
<td></td>
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<tr>
<td>• 1 in 4 families of palliative home care patients experiencing high distress (interRAI)</td>
<td></td>
</tr>
<tr>
<td>• 1 in 5 patients receiving palliative care services with a prognosis of death of 6 months or less experience daily, severe pain (interRAI)</td>
<td></td>
</tr>
<tr>
<td>There is an imbalance between supply and demand: evidence of geographical inequity and potentially an opportunity for improved quality (e.g. reduce LOS in hospice and hospital settings for exacerbations and prior to death)</td>
<td></td>
</tr>
</tbody>
</table>

| **27,000 EOL frailty/dementia deaths** | Different EOL strategies/resources required compared to cancer - more embedded within entire frailty/CDM trajectory |
| • 2/3 of dementia deaths in LTCHs. Of remaining 10,000 community-dwelling frail or dementia patients, most die in hospital - often with implications for ALC beds |
| • Median length of survival range from 7 to 8 years; terminal events resemble exacerbations means few |

**Creative use of alternatives to support people at home (and possibly delay or avoid in-patient hospice stays):**

- Home Care: higher levels/costs of nursing/PSW home care linked to reduced hospice and hospital use
- Integrated Teams with “House Calls” and “Hospital/Hospice at home” capacity

**Access to alternative home like settings in last weeks of life:**

- Re-profiling existing beds and capacity within the system e.g. Hospice friendly hospitals and LTCHs: home-like hospice environments (and related staffing models) within inpatient facilities. [Comparable success stories: high C-section rates in general maternity units compared to family-friendly birthing centres; “swing bed” use under hospice direction compared to regular bed use]
patients are formally identified for palliative care (but some anecdotal evidence of increased demands from families).

27,000 EOL organ failure deaths
- Characterized by unpredictable decompensation pattern followed by varying degrees of recovery; clinical prediction/survival probability estimates ineffective
- Majority likely die in hospital - often with implications for ALC beds

<table>
<thead>
<tr>
<th>LTCH tool-kit</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Frailty/dementia in primary care: ACG markers?</td>
</tr>
</tbody>
</table>

**Integrated, team-based care in the home, LTCH, or other residence**
- Access to gold standard integrated geriatric or CDM care
- Integrated community basket of services including public health, home care, community support, community physician/NP teams, capacity for “House Calls”, pharmacy, coordinated specialist and out-patient care WITH coordinated access to outreach hospice services including volunteer visiting, palliative homecare and professional outreach programs for consultation/mentorship (different models possible including integrated geriatric care teams with capacity for supportive deaths at home OR integrated primary care and specialist hospice outreach teams OR residential/assisted living/LTCH support with integrated EOL care etc)
- Integrated caregiver support including day hospice programs (group services, often at residential hospice facilities, providing supportive activities and respite for family caregivers) and access to short-term inpatient respite care (short-term LTCH beds)
- On-going acuity-related access to specialized, intensive support to manage acute exacerbations, restorative care and stabilization (different models possible including short-term acute inpatient care OR Hospital at Home level care OR assess and restore, etc)
- Access to residential inpatient care in last weeks of life: for many patients EOL not predictable or recognizable – often care may look similar to restorative or stabilization care above

More hospice-friendly assistive living and supportive housing options?

<table>
<thead>
<tr>
<th>POSSIBLE OPTIONS “Level 1” residential, home-like, inpatient palliative care OR integrated supportive housing/EOL care OR community sponsored social care networks OR some combination of the above to serve:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- 26% of seniors who live alone (2006 Census Data)</td>
</tr>
<tr>
<td>- 4% of older adults who are “unbefriended elderly”</td>
</tr>
<tr>
<td>- 1 in 5 home care patients who are socially isolated</td>
</tr>
<tr>
<td>- Patients with advanced or late stage disease who are deprived socioeconomically</td>
</tr>
<tr>
<td>- Hospice-friendly assistive living and supportive housing options?</td>
</tr>
</tbody>
</table>

People can’t be supported to have a home death unless they have a home; have people at home to care for them; and want to die at home

People can’t be supported to have a home death unless they have a home; have people at home to care for them; and want to die at home

People can’t be supported to have a home death unless they have a home; have people at home to care for them; and want to die at home
B. Population-Based Hospice Bed Capacity Benchmarks

**Supporting Research and Analysis**

**Possible Place of death optimization goals**

Assuming about 100,000 deaths (based on 2013 population levels)

25,000 deaths in specialized or acute hospital settings
- Includes people who die suddenly or with an unknown trajectory, as well as 15% of patients from all other death trajectories
  - 10,000 deaths in “regular” hospital (ER, acute, CCC)
  - 15,000 deaths in Highly Specialized inpatient setting (Complex “Level 3” palliative)

12,000 deaths in an alternative “home like” inpatient setting
- Requires a certain level of predictability regarding imminent death so that a request to transfer to an alternative “home-like” residence can be actioned (i.e. primarily relates to the cancer trajectory, similar to the current population served by residential hospices)
- Includes about ⅔ of the patients on the cancer trajectory who can’t or do not wish to die at home but who do not require hospital level care (just over 10,000) as well as a small number of other patients whose imminent death is relatively predictable
- The implication is that the target population currently served by residential hospices will not change significantly although the proportion of cancer patients relative to others may slowly decline over time, assuming current mortality trends continue. In addition, as the system improves its capacity to care for people at home, it is expected that residential hospices will increasingly provide support to marginalized populations who have insufficient resources to die at home, who may have relatively lower levels of acuity compared to the population being served currently.

63,000 patients supported “at home” (including deaths in private residences, LTCHs, retirement homes, supportive housing etc – may also include patients supported by an in-home care team who die in hospital after being admitted for management of an acute care episode)
- Includes people in the last weeks and days of life who wish to die at home, as well as all other patients where imminent end of life cannot be anticipated or predicted
- 50% of community-dwelling cancer patients who wish to die at home (about 10,000 deaths)
- 15,000 deaths in LTCH (including 2/3 of patients with frailty/dementia)
- Remainder includes most patients with dementia and about 85% of patients on the organ failure trajectory – i.e. excluding those requiring hospital level care

Current data about patients based on trajectory of death (from interRAI data)

29,000 end-of-life cancer patients
- The majority of patients with advanced cancer do seem to be identified for palliative care services. 75% of palliative home and community patients have cancer (15,000); 85% of residential hospice users have cancer with mid to higher acuity (2,000); regional cancer centres provide outpatient palliative care services exclusively to cancer patients
27,000 end-of-life frailty/dementia patients
• 2/3 of dementia deaths occur in LTCHs. Of remaining 10,000 community-dwelling frail or dementia patients, most die in hospital

27,000 end-of-life organ failure deaths
• Majority likely die in hospital

17,000 other or unknown trajectory deaths
• Majority likely die in hospital

Supporting Research:
• About 10,000 patients will die suddenly or unexpectedly, most of these in hospital (based on trajectory of death research).
• About 15% of the palliative care population may have complex needs requiring intensive services of a hospital or hospital-based palliative care unit.\(^\text{40}\)
• Prognosis of imminent death (and therefore determination of suitability for residential hospice care) is generally made for patients within an advanced cancer trajectory. Death in patients with frailty/dementia as well as diseases resulting in chronic organ failure, such as chronic obstructive pulmonary disease, congestive heart failure, and end-stage liver disease, tend to run a more fluctuating course and result in death in a less predictable time.
• Even where prognosis of death can be determined, despite equal access to gold standard palliative home care, research suggests that about 50% of the study population will still require or desire alternative care settings in terms of place of death.\(^\text{41}\)

Detailed Analysis
• By the last month of life, 15% of patients facing imminent end of life (15,000) will require highly specialized, tertiary, inpatient palliative care— including 7,000 patients from CCC and 3,000 patients from LTCH with the balance (or about 5,000) from the community.
• 85% (or 17,000) of approaching patients approaching end of life in LTCH should be enabled to die in their LTCH.
• Of the remaining 58,000 community-dwelling patients approaching end of life, about ½ (29,000) will want and are suitable to remain home until they die and (29,000) will want to die in an alternative non-acute inpatient setting.
• Of the 29,000 who want to die in an alternative non-acute inpatient setting, most die in hospital; about 3,000 patients, mostly with higher acuity, die in a community residential hospice (called level 2 palliative for the purposes of this discussion).

\(^{40}\) National Council for Hospice and Specialist Palliative Care Services 1999
\(^{41}\) D Howell et al, 2011
### C. Current Ratio and Location of Existing and Planned Residential Hospice Beds in Ontario

<table>
<thead>
<tr>
<th>LHIN</th>
<th>How many Residential Hospices are in Operation?</th>
<th>Current Beds</th>
<th>Planned Beds</th>
<th>Total Beds (In the future)</th>
<th>Total Ratio per 100,000</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sites</td>
<td>Beds</td>
<td>Sites</td>
<td>Beds</td>
<td>Sites</td>
<td>Beds</td>
</tr>
<tr>
<td>PIER ST. CLAIR</td>
<td>2</td>
<td>18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SOUTH WEST</td>
<td>3</td>
<td>26</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WATERLOO WELLINGTON</td>
<td>2</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HAMILTON NIAGARA</td>
<td>5</td>
<td>42</td>
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<td></td>
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</tr>
<tr>
<td>CENTRAL WEST</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>MISSISSAUGA HALTON</td>
<td>3</td>
<td>18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TORONTO CENTRAL</td>
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</tr>
<tr>
<td>CENTRAL</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>CENTRAL EAST</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SOUTH EAST</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NORTH SIMCOE MUSKOKA</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NORTH SIMCOE MUSKOKA</td>
<td>2</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NORTH EAST</td>
<td>2</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NORTH WEST</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provincl Total</td>
<td>37</td>
<td>272</td>
<td>196</td>
<td>1.976</td>
<td>58</td>
<td>468</td>
</tr>
<tr>
<td>Total approved hospice</td>
<td>26</td>
<td>212</td>
<td>8</td>
<td>80</td>
<td>34</td>
<td>292</td>
</tr>
<tr>
<td>Total - Not approved, but LHIN funded</td>
<td>7</td>
<td>49</td>
<td>4</td>
<td>32</td>
<td>11</td>
<td>81</td>
</tr>
<tr>
<td>Total - Community funded, no public funding</td>
<td>4</td>
<td>11</td>
<td>9</td>
<td>84</td>
<td>13</td>
<td>55</td>
</tr>
</tbody>
</table>

**Legend**

- Ministry approved hospice
- Not approved, but LHIN funded
- Community funded, no public funding
NOTE: Table C is intended to reflect a snapshot of the residential hospice landscape in Ontario:

The **Planned Beds Column** illustrates 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 on pages 40-42 of this report.

The **Ministry Approved** hospice beds in the **Planned Beds Column** reflect MOHLTC funding that is available for residential hospices. It is noted that LHINs in consultation with the local community may not be utilizing this funding for residential hospice expansion at this time.

It is further noted that LHINs in consultation with the local community may re-profile this funding for other palliative care services that address local needs.

The **Community Funded** beds of the **Planned Beds Column** reflect beds that are in planning without formal LHIN support at present.

**D. Leading Practices for Team and Community-Based End-of-Life Care**

All communities, teams and providers should be supported to advance pragmatic efforts to do a little better tomorrow compared to today while working towards an exemplary or “Gold Standard” over time.

**Leading Practices for Teams**

- The patient and family will choose what role they wish to play in terms of coordinating their personalized team – depending on their preferences, they may take on an active self-management role, engage in shared decisions with a trusted provider, or use a professional care coordinator. The team quarterback will work to ensure continuous care coordination, monitoring and care management over the entire EOL journey and provide a consistent communication channel back to the patient and family across the entire circle of care. For each patient and family, the role of the patient and family nominated quarterback will be streamlined in relation to other system-level coordination processes such as through Health Links or home and community sectors – (for example, see MOHLTC Policy Guideline for CCAC and CSS Collaborative Home and Community-Based Care Coordination, 2014).

- The patient’s virtual personalized team exists organically, synergistically and simultaneously with formal health care teams. The availability of formal, integrated, community-based healthcare teams helps, but is not a required antecedent condition. The inclusion of formal specialized teams within the patient’s personalized team will often be for time-limited consultation and support, with the majority of the patient’s on-going care delivered through informal, community and primary care processes, particularly during the early and intermediate stages of the patient and family journey.
A core set of team members will take formal ownership and accountability for the patient and family experience of care throughout their journey, as well as achieving other important patient and patient-focused outcomes.

Each team member will work within a continuously updated Personalized or Coordinated Care Plan that sets out information about the overall set of services and activities being provided to meet the needs and goals of a patient. It outlines how the different activities are organized and sequenced and identifies the specific roles and responsibilities of each formal and informal provider comprising the patient’s “personalized” team.

Patient care planning, including advance care planning and goals of care, should be discussed with patients and their informal caregivers early, frequently, and as circumstances change, recognizing that involvement in planning to optimize quality of life approaching death can be therapeutic for patients and families. Goals should be explicitly recorded in the patient’s care plan. The care plan should be continuously evaluated against its capacity to deliver on the goals which have been prioritized by the patient and their families.

Teams should be empowered to experiment with many different ways to fulfill their commitment of quality to patients and families – and measure themselves on the impact of those choices. Experimentation and feedback are key to real improvement – along with the discipline to work across boundaries, involve a wide range of perspectives, learn fast, and fail intelligently.

The success of teams is entirely relationship driven – teams pay attention to the known factors that enable successful high performing teams to be successful (such as trust, communication, respect, flexibility, continual improvement, seamless system navigation, shared vision, holistic approach, proactive, education, etc).

Teams must be anchored in and exist within the larger community ecosystem and are not defined by composition, size, funding, or affiliation with host organizations. Teams are built on local strengths and assets – and must be seen as organic, adaptive and evolving sets of relationships and processes. The patient’s team continues over time and is likely to cross multiple care settings, although some supporting resources may change once the patient transitions in and out of different services. For the majority of patients for the majority of time, teams will be drawn from organizations physically situated in the community. For a minority of patients for a minority of time, teams will be primarily drawn from resources within the patient’s LTCH, hospital setting, or residential hospice. Even in these situations however, community involvement should not stop at the door but continue to support the patient through whatever episodes of care they might experience in these specific settings.

In successful teams, team members will be able to self-identify simultaneously in a synergistic, balanced way with their individual organizations; their broader team partners; and with their community. Where this cannot be accomplished, issues should be brought forward for discussion at both team and community hub levels for broader collective problem-solving and resolution.

Leading Practices for Community Networks or Hubs

- All organizations within the hub will share a deep attachment, affiliation and sense of belonging to the collective “community”.
- Through the functions of the community hub, patients and families, residential hospices, Health Links, home, community and social services, primary care, long term care homes, hospitals, residential services, and the non-profit sector will be collaboratively engaged to
build awareness and better understand the roles and responsibilities of each partner in delivering an integrated continuum of end-of-life care within communities. Researchers, evaluators, educators, and technology and business leaders will be similarly engaged in these conversations.

- Each organization that participates as part of the hub commits to being accountable to all other partners for its participation within an organized, integrated end-of-life continuum of care. Each organization accepts responsibility for its contribution to shared population and system outcomes, regardless of which organization has funding and accountability for the delivery of unique services.

- End-of-life community hubs will establish an empowerment culture and set collective priorities for improving the way care and services are organized for end-of-life populations in a manner that is customized for the unique needs of their populations and geographies. Specifically, the Hub will have oversight for the broad cross-boundary patterns, relationships and the culture of collaboration within the community’s virtual “integrated community services ecosystem” (in which a variety of services are widely available and known, can be mixed and matched depending on specific patient and family needs and preferences at specific times, and a variety of players work together and fully use their expertise to best meet the needs of the patients within their communities - see model description below). This includes delivery practices across organizations, and reciprocating processes to build capacity for early identification and upstream care – ensuring practical steps are taken to make the different components of an end of care continuum within that community work better for patients in meaningful ways. At a community-level, organizational processes and practices should be established to enable patients, families and care coordinators to easily access and draw down time limited or on-going resources to create their personalized teams.

- Community hub leadership should be invited to participate in all health and social service planning tables that affect the provision of palliative services and care at the end of life.

- The Community hub will support a formal community-wide program of excellence in palliative and end of life care, including engaging in community capacity-building (e.g. leadership and subject matter expertise), shared learning (e.g. education, training, certifications, team building, etc), knowledge management and exchange (e.g. facilitating the collection of standards, practices, knowledge repositories, and outcome metrics), knowledge translation support, research, public communication, and processes for continuous improvement.

- Administrative and organizational support for the Hub will be delivered through an agreed upon “backbone support organization” to ensure the community continuum is organized for collective impact (i.e. with a common agenda, shared measurement/feedback loops, mutually reinforcing activities, and continuous communication).

- Communities should be given a significant degree of flexibility in how the hub model would be organized depending on regional and local priorities and choices – i.e. which organization is the “backbone”; the physical location of the gathering space; collaboration processes etc.

- For communities with community-service oriented voluntary and residential hospices, we would expect the hospice to take a lead role in organizing the local network of integrated community palliative and end-of-life services, unless another model is determined for that community.
For communities without existing community-integrated hospices but with hospice programs “in process”, it is important to leverage those local and existing grassroots efforts within the context of this broader purpose.

For communities with neither an existing hospice nor one in process, it is important to take a health and community assets approach to identify other suitable leadership models.

The EOL community hub will exist organically, synergistically and simultaneously with formal health care and social service structures. The hub is built on local strengths and assets and must be seen as an organic, adaptive and evolving structure and set of relationships.

It should be fully aligned with any Health Links structures within the same community. End-of-life community hubs and Health Links target complex patients and will work proactively to better coordinate care and prevent sub-optimal resource use. The proposed end-of-life community hub will support the work of Health Links by focusing on normalization and de-medicalization of end of life care and working across social care, non-profit and business sectors.

It may be initially developed as a stand-alone effort specific to aging and end of life care, but should be aligned with any broader emerging policy on community hubs, reflecting the perspective of health and wellness.

Working Towards a “Gold Standard” of Care

For example, 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.

The GSF is based on the seven C’s of care, regardless of the setting of care: communication, coordination, control of symptoms, continuity of care, continued learning, caregiver support and care of the dying pathway. More specifically it helps health care organizations achieve standards of care across care settings that are aligned with quality outcomes for palliative care.

The GSF focuses on the needs of patients in their last year of life, regardless of their diagnosis. The goal of GSF is to help organizations improve things such as: patients’ pain and symptom management, the likelihood of dying in the patients’ place of choice, avoiding crisis and ED/hospitalization, improved health service provider support and coordination, and improved coordination and communication between providers.

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

The 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 patients; improved communication, coordination and integration across settings of care; and improved outcomes for patients which allows them to live and die where they choose resulting in reduced hospitalizations and cost.
Appendix B – Residential Hospices Working Group Terms of Reference

**Project Name**
Advancing High Quality and High Value Palliative Care: **Residential Hospice Working Group**

**Project Sponsor**
Ministry of Health and Long-Term Care
Local Health Integration Networks

**Target Project Completion Date**
Summer 2014

**Project Manager**
Debra Bell, Manager, Implementation Branch

**Version No.**
3.0

**Version Date**
November 2, 2013

**Overview**
The Residential Hospice working group is a key delivery component of the Declaration of Partnership and Commitment to Action (the Declaration), a consensus document that outlines shared priorities and actions for partners to take in order to achieve a shared vision for improving palliative care delivery in Ontario.

As the change agents for policy development, planning, funding and integration, the Ministry of Health and Long-Term Care (ministry) and Local Health Integration Networks (LHINs) are leading efforts to establish a residential hospice policy framework and integration options.

**Mandate and Deliverables**
The Residential Hospice Working Group will provide analysis and input 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 aligned with Ontario’s Declaration of Partnership and Commitment to Action.

A community-based residential hospice is a home-like environment where adults and/or children with life-threatening illnesses receive end-of-life care services. This may include free standing residential hospices; hospices co-located with other health facilities such as hospitals or long-term care homes; and hospices that offer a range of residential and non-residential community services (i.e. visiting hospice or specialized outreach teams in addition to residential programs). While the mandate of the Working Group does not include consideration of programs and standards in other care settings (such as personal residences, acute care or complex continuing care, long-term care, supportive housing, homeless shelters or any other institutional settings for patients with end-of-life care needs), the optimal role of community-based residential hospices in relation to these other settings within a defined continuum of care will be considered.

The Working Group deliverables include:

- Detailed analysis of the current state of community-based residential hospices, including:
  - Baseline data/information on: current patient profiles, current hospice models and resources, cost of care delivery, and care outcomes including any existing impact analyses (avoidable hospitalizations, etc.);
  - The relative mandate of different palliative providers/settings to ensure residential hospices are adding value, avoiding duplication, and maximizing access;
  - An evaluation of the current roles and accountability relationships in the palliative sector (the role of
Mandate and Deliverables

- Residential hospices in particular, but also the roles of the CCACs, the LHINs, the hospitals, long-term care homes, primary care, etc.) to understand the larger picture of how the system should be structured and what impact that structure will have on existing providers and relationships;
- 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, including consideration of:
  - Person-directed and family-supported care preferences
  - Planning assumptions to optimize targeting of resources within a continuum model based on population needs and preferences;
  - Options for improving consistency within existing residential hospice practices;
  - Options for improving the balance between supply and demand for residential hospice beds that will be responsive to demographic changes in the future;
  - Strategies to share resources or other collaborative models to avoid or reduce pressure for new capital investments;
  - Strategies to optimize community-based primary care and volunteer capacity;
  - Models for rural, northern/remote areas, and for marginalized populations; and,
  - Opportunities to advance “Centres of Excellence” approaches in palliative care.

Timeframes and Logistics

High-level timeframes

- **Fall 2013** – Initial meeting to review Terms of Reference and key inputs (including literature review); review scope of working group and establish structure/format to achieve deliverables.
- **Winter 2013** – ‘Current State’ section of Business Case completed, which includes:
  - Scan of current delivery models
  - Baseline data on care delivery
  - Baseline data on current patient profiles
- **Winter 2013/14** – First draft of ‘Evidence-based Best Practice’ section completed
- **Summer 2014** – Focus groups and Steering Committee input.
- **Fall 2014** – Input shared with the ministry, LHINs, the sector and the Coalition through the Provincial Palliative Steering Committee.

Reporting Processes

- The Working Group report will be shared at the end of the process with the ministry, the LHINs, the Coalition and residential hospice sector through the Palliative Provincial Steering Committee. To ensure ongoing alignment with the Declaration, regular progress updates will be provided to the Steering Committee.

Working Group Consensus

The Working Group is asked to reach consensus on final deliverables for review by the Provincial Palliative Steering Committee co-chairs. For items where consensus cannot be reached, the process will be as follows:

- The Working Group will be asked to state the nature and extent of the disagreement.
- If appropriate, the Working Group co-chairs will escalate the issue to the Provincial Palliative Steering Committee for resolution.
Timeframes and Logistics

Supports
- The ministry will facilitate meeting spaces and teleconference lines and provide secretariat support for the meetings of the Working Group.
- The ministry will update the Directory of Networks (DoN) to:
  - Enable participants to exchange ideas on-line, connect with other working groups (if need be) and collaborate on shared tasks
  - Monitor progress on milestones for quarterly reporting of deliverables

<table>
<thead>
<tr>
<th>In-Scope</th>
<th>Out-of-Scope</th>
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</table>
| • Advice to inform community-based residential hospice policy; integration options; and sector best practices - See “Mandate”. | • Capital investments
  • New funding or funding policy
  • Legislative and regulatory drafting
  • Operational level decision making |

### Residential Hospices Working Group members

<table>
<thead>
<tr>
<th>#</th>
<th>Name</th>
<th>Role</th>
<th>Organization</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

A series of focus groups will also be planned 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. See Appendix A for a preliminary list of focus groups. Further planning of the focus groups will be undertaken in the Working Group.
### Appendix A: Focus Groups

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Purpose</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice Palliative Care Ontario Residential Hospice Interest Group Focus Group</td>
<td>To consider how to optimize care provided in Ontario’s residential hospices, including the needs of clients and caregivers and diverse communities, in the context of a robust and comprehensive end-of-life continuum of care.</td>
<td>April 26, 2014</td>
</tr>
<tr>
<td>Provincial End of Life Care Network/Local Health Integration Network Leads Focus Group</td>
<td>To consider how to optimize care provided in Ontario’s residential hospices, to meet the needs and preferences of clients and caregivers and diverse communities, in the context of a robust and comprehensive end-of-life continuum of care.</td>
<td>April 30, 2014</td>
</tr>
<tr>
<td>Researchers Focus Group</td>
<td>To consider how to optimize care provided in Ontario’s residential hospices, including the needs of clients and caregivers and diverse communities, in the context of a robust and comprehensive end-of-life continuum of care.</td>
<td>July 18, 2014</td>
</tr>
<tr>
<td>Hospice Palliative Care Provincial Steering Committee Focus Group</td>
<td>To seek input on how to strengthen Ontario’s end of life continuum of care, including consideration of the role of residential hospices in relation to the role of community agencies, hospitals, LTCHs, and primary care</td>
<td>September 16, 2014</td>
</tr>
<tr>
<td>Health Links Focus Group</td>
<td>To provide input on how end-of-life care can best be organized and strengthened while optimizing opportunities to align with Health Links.</td>
<td>October 28, 2014</td>
</tr>
<tr>
<td>Addressing the Needs of Diverse Groups and Geographies</td>
<td>To provide input on how end-of-life care can best be organized and strengthened to meet the diverse needs of communities and populations.</td>
<td>October 28, 2014</td>
</tr>
<tr>
<td>Addressing the Needs of Patients and Caregivers Focus Group</td>
<td>To consider the preferences of patients and caregivers to optimize care provided in Ontario’s residential hospices.</td>
<td>October 29, 2014</td>
</tr>
<tr>
<td>First Nations Focus Group</td>
<td>To provide input on how end-of-life care can best be organized and strengthened to meet the diverse needs of First Nations communities.</td>
<td>October 30, 2014</td>
</tr>
</tbody>
</table>