# Champlain Hospice Palliative Care Action Plan 2014-2019

***By the Champlain Hospice Palliative Care Program***

***July 2014***

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# 1. Foreword

### A message from the Chair of the Champlain Hospice Palliative Care Program Board

In 2010, the Champlain Local Health Integration Network brought the challenge of managing end-of-life care for citizens of the Champlain region front and centre. It provided the Regional Hospice Palliative Care Program with the mandate and resources to integrate and better coordinate the delivery of hospice palliative care in all settings.

Since then, the Champlain Hospice Palliative Care Program actively engaged many stakeholders to identify and address key issues in order to provide easier, timely, and more access to coordinated hospice palliative care to all residents of Champlain. This Action Plan is the outcome of these consultations and focuses on providing equitable access and building capacity across care settings.

Over the next five years, implementation of this plan will aim to ensure that there will be comprehensive hospice palliative care available to all residents of Champlain. It will ensure that across Champlain people can live out their lives with quality care, and with as much dignity and comfort as possible. It will also position Champlain to become a region of excellence, which can be leveraged across the province.

Achieving these changes will require sustainable funding to provide the highest quality hospice palliative care the plan outlines.

Most importantly, it will require strong leadership, partnership and cooperation among all stakeholders. We all will need to "lift our game" to enable change. This Strategy and Action Plan illustrates the direction we need to take.

Sylvie Lefebvre
Board Chair

# 2. Key recommendations at a glance

The recommendations in this Action Plan are the result of an analysis of evidence and consultations with multiple community and health system partners and stakeholders over the last three years. Recommendations have been organised into three focus areas to advance comprehensive hospice palliative care across Champlain over the next five years.

### Focus Area 1: Equitable access to hospice palliative care

Hospice palliative care services need to be designed to be accessible to all who need them and have sustainable funding. Specifically, we need to:

1. *Ensure hospice palliative care services are responsive to the diversity of all residents of Champlain. This includes: urban, rural and remote populations; Francophone and other culturally/linguistically diverse populations; Aboriginal communities; and other vulnerable populations, such as children, individuals living with disabilities, GLBTQ and the homeless.*
2. *Provide sustainable funding for residential hospices by increasing funds to a minimum of 80% of total operating costs.*
3. *Establish dedicated funds to develop and/or enhance inter-professional palliative care teams in hospitals across Champlain.*
4. *Develop a strategy to engage primary care providers to provide palliative care to their own patients.*

### Focus Area 2: Hospice palliative care across a full continuum of care

A comprehensive continuum of care is required to support more individuals who desire to remain in their communities until the end of their lives. This support is for individuals, caregivers and their families from diagnosis through to and beyond death. Specifically, we need to:

1. *Enhance in-home palliative care services.*
2. *Increase access to day hospice and home visiting services.*
3. *Increase the number of residential hospice beds across Champlain.*
4. *Ensure the staffing level for the tertiary Palliative Care Unit is appropriate to meet the complex physical, social and spiritual needs of individuals and their families.*

### Focus Area 3: Capacity building across care settings

Building capacity across our health care system will develop a strong and sustainable foundation for which to build enhanced hospice palliative care services. Specifically, we need to:

1. *Implement a public awareness campaign in Champlain about hospice palliative care, advanced care planning, and how to access local services.*
2. *Finalize and implement a regional bereavement plan.*
3. *Enhance capacity at the primary level to provide palliative care services.*
4. *Implement and promote a regional strategy and standards for palliative care education across care setting, across professionals, and from school to the workplace.*
5. *Implement and monitor targeted standards and performance indicators.*

6. *Implement the rural framework to build capacity in rural communities.*
7. *Assess the feasibility to implement electronic tool to integrate services.*
8. *Support the development of volunteer programs.*

# 3. Introduction

The Champlain Local Health Integration Network (LHIN) has identified hospice palliative care as a priority in their Integrated Health Service Plan 2013-2016. Specifically, the LHIN is working to ensure "more people at end of life, families and caregivers receive palliative care supports in their setting of choice". The Champlain Hospice Palliative Care Program has been given the mandate from the Champlain LHIN to set strategic directions and coordinate hospice palliative care services to achieve this goal.

The Champlain Hospice Palliative Care Program (The Regional Program) has been collaborating with community members and partners to provide a comprehensive continuum of hospice palliative care services in Champlain since its inception in 2010. We are working towards a hospice palliative care system that is accessible, integrated across the region, sustainable, high quality, and improves the health and quality of life of individuals, families, and caregivers both preceding and following death.

Under the leadership of The Regional Program, and with the support of multiple partners and the Champlain LHIN, there has been significant progress to advance and integrate hospice palliative care services across Champlain since 2011. For example:

- *An integrated hospice was established in Ottawa which expanded community hospice services, increased the number of residential hospice beds at Hospice Care Ottawa from nine to nineteen, and contributed to the development of a centralized access point for hospice palliative care in Ottawa.*
- *A unique model to provide residential hospice services in Barry's Bay, a remote community in Renfrew County, was developed and implemented.*
- *Volunteer visiting services and community hospice programs were expanded in Kemptville.*
- *Hospice palliative care services in hospitals and hospices across 12 program sites have been connected through the Ontario Telemedicine Network with support from The OutCare Foundation and the Champlain LHIN.*
- *Palliative Care Nurse Practitioners were integrated with the well-established Palliative Pain and Symptom Management Team to create the new Regional Palliative Consultation Team to support capacity building among primary care providers.*
- *Standards and indicators were developed for our local hospice palliative care organizations to support regional planning and organizational quality improvement initiatives.*

This Action Plan is the result of an analysis of evidence and consultations with multiple community and health system partners and stakeholders over the last three years. Prioritized recommendations are identified in this Action Plan to advance hospice palliative care across Champlain over the next five years. Thanks to the many individuals and organizations that contributed to the development of

this plan by identifying local successes, challenges and potential solutions to enhance hospice palliative care for all people in all areas across Champlain. It would not have been possible without you.

This Action Plan builds on two cornerstone documents: 1) The inaugural *Champlain Hospice Palliative Care Program Plan* (May 2010); and 2) *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (December 2011)[1]. The inaugural plan set out a vision to strengthen and coordinate end of life care across Champlain and was instrumental in the establishment of The Regional Program in 2011. The *Declaration of Partnership* outlines guiding principles, goals, and specific action commitments for Regional Hospice Palliative Care Programs, LHINs, Ministry of Health and Long Term Care, and other hospice palliative care stakeholders across Ontario.

This Action Plan is designed to be used by both health system planners and local organizations to advance hospice palliative care in Champlain aligned with our regional vision.

# 4. Importance of Hospice Palliative Care

Hospice palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals, families and caregivers to:

- *Enhance quality of life prior to death by addressing the physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;*
- *Prepare for and manage self-determined life closure and the dying process;*
- *Cope with loss and grief during the illness and bereavement; and*
- *Die with dignity in their place of choice*[1].

Despite significant progress to advance hospice palliative care both locally and provincially over the past years, there continues to be inadequate and inequitable access to integrated and comprehensive hospice palliative care. Furthermore, it is expected the demand for hospice palliative care will increase as a growing percentage of our population gets older and more individuals are living with chronic disease. It is estimated that only 16-30% of Canadians have some level of access to hospice palliative care and the majority of deaths currently occur in hospital[2].

For *individuals at end of life*, access to hospice palliative care can mean: a better quality of life; care that is less aggressive and more consistent with their preference; and the ability to receive care and die in their place of choice.

Support for families and caregivers is also inadequate and inconsistent. It is estimated more than 150000 family members and friends across Champlain are currently providing care —including those caring for someone at end-of life[3]. Given our aging population, the number of caregivers and the burden on those caregivers is expected to increase.

For *families and caregivers*, access to hospice palliative care can mean: enhanced support to reduce the emotional, physical and psychosocial stresses; respite; confidence the end of life care plan is in accordance with their loved ones' wishes; and improved bereavement.

Lastly, the current system is not integrated or resourced enough to provide comprehensive hospice palliative care from diagnosis to end of life to bereavement for all who need it.

For *the health system*, access to an integrated continuum of hospice palliative care services means: improved client and family experience; improved health outcomes; and more cost effective health care.

# 5. Strategic Directions

## Our Vision

The vision established for advancing hospice palliative care in *The Declaration and Commitment to Action* (Dec 2011) is:

> *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.*

## Our Values and Assumptions

The following values and assumptions from *The Declaration of Partnership* guided the development of this vision and our own Action Plan:

1. *All Ontarians should have equitable access to high quality care and support to optimize their ability to live well with a progressive life-limiting illness wherever they reside or receive care.*
2. *The individual with a progressive life-limiting illness and their family are at the centre of care.*
3. *Family members, friends and community groups provide most of the care needed.*
4. *Quality is a key driver to achieve system goals.*
5. *Increasing sustainability and value is a central focus of improvement.*

## The importance of building a regional system

Implementing a regional approach to health planning and service delivery is an effective way of enabling health systems to make significant improvements in health care delivery. Regionalization promotes a broader approach to health systems design; rather than focusing on individual providers and organizations, it promotes planning and coordination of services to meet population needs that can continuously adjust in dynamic and sometimes unpredictable ways.

This approach has yielded significant success in palliative and end-of-life care where innovators in jurisdictions across the world, such as Edmonton and Surrey (Canada), Australia, New Zealand, and Catalonia and Estremadura (Spain) have adopted such an approach since the early 1990s[4-6]. Results have included improved access to and quality of hospice palliative care services, significant reductions in acute care hospitals as the place of death for individuals with cancer, increased access to hospices and palliative home care services and significant cost-savings for their respective health care systems. We can learn from and adapt the best practices from this global work to meet the needs of residents in Champlain.

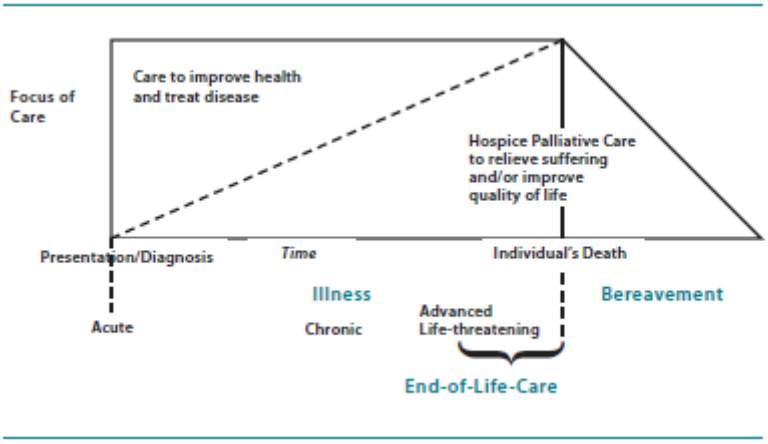
The Champlain Hospice Palliative Care Program was the first Regional Palliative Care Program established in Ontario. We hope to create a "region of excellence" as we leverage our community strengths and the work of multiple partners to create an effective system of hospice palliative care. See Appendix A for a list of individuals and organizations consulted during the development of this Action Plan.

## Proposed Hospice Palliative Care System

Excellent hospice palliative care has the same elements as excellent chronic disease management. Our health care system must shift to a model that integrates hospice palliative care and support for adults and children with chronic disease across the full continuum from diagnosis until death and through bereavement.

The needs of individuals with progressive life limiting illnesses vary across the illness trajectory. For some, the trajectory may be relatively short (i.e. weeks to months), but for others it may be many months and even years. Diagram 1 depicts how both chronic disease modifying treatments and hospice palliative care align along the illness trajectory to provide different levels of support at diagnosis through to and beyond death.

***Diagram 1: Child & Adult Hospice Palliative Care – Chronic Disease Continuum Model***




Source: *The Canadian Hospice Palliative Care Association (2002)*

## Recommended Hospice Palliative Care Service Model

Currently, individuals with advanced chronic disease(s) or complex care needs often receive care that is reactive, targeted, disease-focused, centered on curative treatment, and delivered by multiple individual providers in distinct acute episodes.

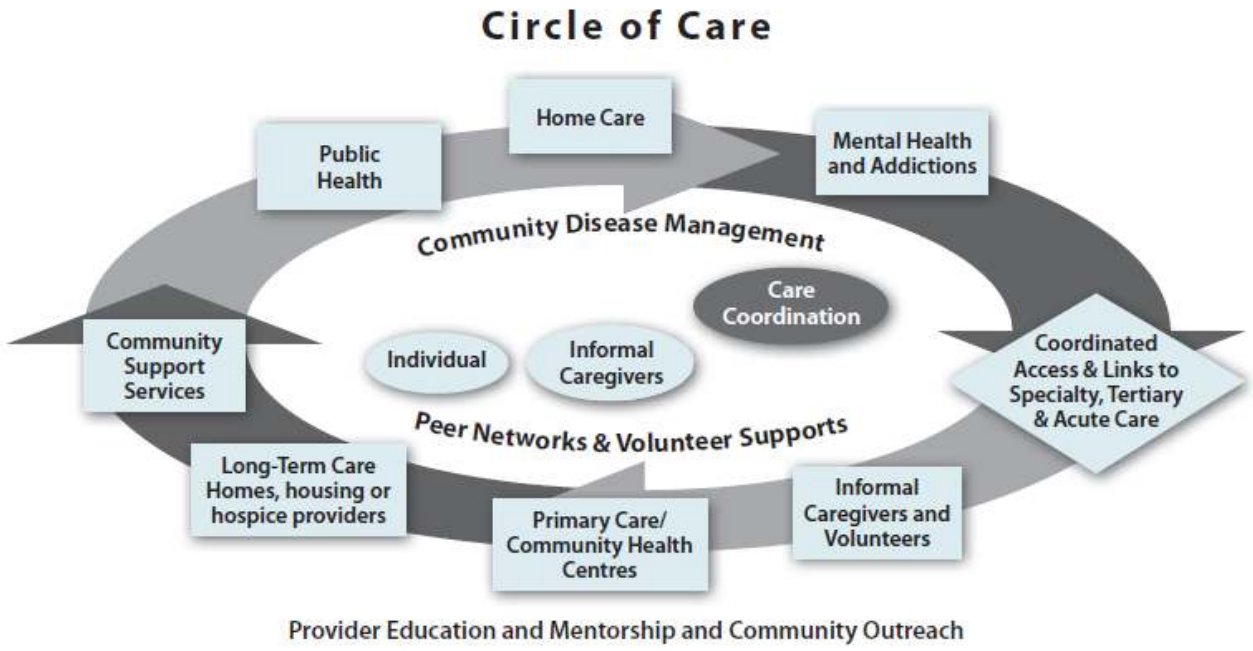
A proposed new model of providing hospice palliative care is to organize "virtual extended inter-professional teams" to wrap delivery around the adult or child and their family and caregivers in accordance with the individuals' preferences for care. In this model, adults and children with advanced chronic disease(s) and their informal support network will receive care and support that is

proactive, holistic, person and family-focused, centered on quality of life and symptom management issues, and delivered by a virtually integrated inter-professional team in a coordinated, continually-updated care plan, that encompasses all care settings in which the client receives care.

Diagram 2 depicts the many partners and systems within the health sector that need to align to provide seamless person- and family-focused care. There is recognition of the important role of family, caregivers and community support services to ensure hospice palliative care is available in a setting of choice.

The focus of this model of care is to improve a person's quality of life and manage symptoms, not just extend life. This model is intended to enable individuals to stay in their home as long as possible, increase access to hospice palliative care across care settings, and reduce the number of deaths in acute care hospitals.

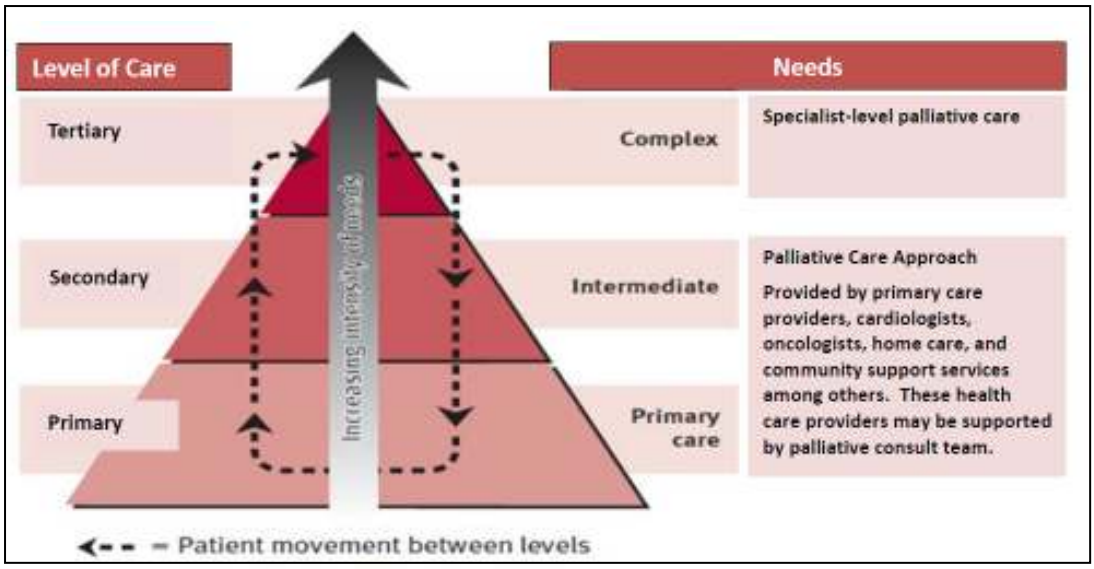
***Diagram 2: Circle of Care – A model for integrated hospice palliative care***




Source: *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (2011,2013)

This circle of care is applicable across all levels of care: primary, secondary and tertiary (see Diagram 3). Most palliative care needs can be addressed at the primary level (e.g. primary care, home care, community support services). We will strive to enhance this circle of care across all levels of care, with a focus on building capacity at the primary level with support from regionally organized specialist resources.

*Diagram 3: Levels of Palliative Care*




Source: Adapted from Australian Population-based Palliative Approach Model

## Advocacy as a strategy to advance hospice palliative care

Many system-level issues that impact the quality and delivery of hospice palliative care services are outside of the control of both The Regional Program and the Champlain LHIN. Advocacy is a strategy to influence these system-level factors (e.g. public policy and resource allocation decisions).

The Regional Program has the mandate to advocate for funding to advance hospice palliative care priorities across Champlain. Thus, The Regional Program will advocate for issues that align with the recommendations in this Action Plan on behalf of hospice palliative care providers and organizations.

Specifically, the Champlain Hospice Palliative Care Program will:

- *Support the advocacy efforts of Hospice Palliative Care Ontario (HPCO) to increase adequate and sustainable funding for local residential hospices.*
- *Advocate for sustainable funding and a single region-wide alternate funding plan for physicians to provide hospice palliative care, including consultation, coaching and mentoring of their peers.*

# 6. Implications for Stakeholders

This strategy will have positive impacts on individuals, families, the health system and government.

## How will this Strategy and Action Plan impact these populations?

### *People who are dying and their families*

- Easier, timely, and more equitable access to coordinated hospice palliative care.
- Timely access to quality care that is focused on improving quality of life, comfort, dignity, and spirituality in the setting of choice.
- They are at the centre of a full continuum of care and involved in making their own care decisions regardless of where they reside and access services across Champlain.
- Advanced care planning is integrated into primary care, well ahead of when people will need end-of-life care.
- More convenience and travel time-savings by centralized intake and better matching individuals to the hospice palliative care support that is closer to the place of residence of their caregivers and family members.
- Ongoing involvement of their family physician throughout the disease trajectory.
- Reduced wait times and 24/7 support and assistance from skilled inter-professional teams including after-hours nurse consultation and the possibility of nurse/physician home visits in critical cases.
- Level of assurance that the quality of care meets or exceeds standards; able to expect same level of service quality across Champlain; understanding that mechanisms for accountability and continuous improvement are in place.
- More people are able to die at home. Community-based services provide support to individuals in their homes for as long as possible; when no longer able to stay at home, a residential hospice provides an alternative to meet the needs of end-of-life care.

### *Health Care Providers in Champlain*

- Enhanced capacity through education, knowledge transfer and resources will enable community providers and specialists to focus their efforts on the individuals who are most in need of their specific skillsets.

- More skills for primary care providers, and health care professionals providing them with a greater sense of being valued for their work and easing the burden of compassion fatigue.
- A change in organizational culture will be facilitated, bringing partners together, building relationships and confidence in the partnership model.
- Inter-professional teams will be essential to integrating the palliative care approach and will provide a source of expert advice for family physicians and other community based providers.
- Strong role and more support for family physicians who will take lead responsibility in caring for their patients
- Key roles for nurses and other members of inter-professional teams as program facilitators, care coordinators, home care providers, educators.
- The compassion and commitment of volunteers will play an essential role in making an integrated system work in Champlain to provide care to many more people that would otherwise be reached. A strong volunteer program will need to actively nurtured and supported.
- Common standards, frameworks and assessment tools to provide the foundation for an integrated hospice palliative care approach and continually improve services.
- Accreditation will improve efficiency, accountability and confidence that standard services are being provided.

### *The Health System and Government*

- More individuals and their families will have improved health outcomes and quality of life.
- More people at end of life, families, and caregivers, receive palliative care supports in their setting of choice
- More individuals, families, caregivers, and health care providers will have a positive experience with the health system.
- Shorter stays and reductions in inappropriate admissions to acute care hospitals will translate into more effective and efficient use of health care resources.
- Faster delivery of service improvements and lower overall system costs
- Single access point as well as triage of cases will mean efficient use of resources, less duplication, and more timely care for patients/families.
- Stronger, more consistent policy leads to a more integrated approach to end-of-life care in the community and shifts palliative care from being a specialized service available to a few, to a more general integrated service, available to all people where they live and receive care.

- Accreditation and the implementation of systems to monitor and evaluate will provide reasonable level of assurance that Champlain HPC is well-run and provides good return on investment and providing information on effectiveness, efficiency, and client satisfaction.

# 7. Focus Areas

The strategic directions are supported by a comprehensive plan organised into three integrated focus areas for action over the next five years:

1. *Equitable access to hospice palliative care*
2. *Hospice palliative care across a full continuum of care*
3. *Capacity building across care settings*

These focus areas and respective recommendations provide specific guidance to advance hospice palliative care locally in alignment with the *Declaration of Partnership and Commitment to Action*.

## Focus area 1: Equitable access to hospice palliative care

### *Anticipated Outcomes by 2019:*

- Individuals, caregivers and families will have better timely access to hospice palliative care, regardless of income, culture, health status, or place of residence across Champlain.
- Individuals will have enhanced quality of life prior to death.
- Caregivers and families will be supported and have improved bereavement before and after the death of a loved one.

### *What we need to do to get there:*

1. Ensure hospice palliative care services are responsive to the diversity of all residents of Champlain region. This includes: urban, rural and remote populations; Francophone and other culturally/linguistically diverse populations; Aboriginal communities; and other vulnerable populations, such as children, individuals living with disabilities, GLBTQ and the homeless.

    *1.1. Support the Local Palliative Care Networks in each sub-region across Champlain. These networks engage community members and work collaboratively to identify, develop and implement local solutions and partnerships to ensure hospice palliative care services are responsive to the needs of urban and rural communities. It is recognized that there may be opportunities for these committees to collaborate with emerging provincial initiatives, such as the development of Health Links and Primary Care Networks.*

    *1.2. Enhance access to palliative care services in French by building capacity where needed, leveraging existing resources and integrating the needs of Francophones in the planning of new initiatives/programs.*

    1.3. *Ensure community-based palliative care is planned in collaboration with Aboriginal people, and mechanisms are in place for this care to be flexible to meet the unique needs of each Aboriginal community.*

2. Provide sustainable funding for residential hospices by increasing funds to a minimum of 80% of total operating costs.
   Funding for residential hospices is not consistent across the region and does not provide for all operational costs. As a result, residential hospices are required to fundraise a significant percentage of their operational costs. Financially stable residential hospices can provide high quality care at a lower cost than hospital-based care.

3. Establish dedicated funds to develop and/or enhance inter-professional palliative care teams in hospitals across Champlain.
   Most of the hospitals in Ottawa have palliative care consultation teams. However the current resources cannot meet the current demand or anticipated increased demand. Over the past years, referrals to these teams have been increasing, especially for patients with non-cancer diagnoses. Currently, formal consultation support in small community hospitals outside of Ottawa is inconsistent and often lacking. These teams would provide a continuum of support from consultation, shared care through to substitute (take over) care.

4. Develop a strategy to engage primary care providers to provide palliative care to their own patients.
   Most palliative care needs can be addressed at the primary level. When primary care providers are involved earlier in an individual's care, it is more likely the individual will be connected with timely community resources and the physician will also provide end of life care.

   *4.1. Develop a strategy and support existing initiatives to involve primary care providers early when their patients are receiving treatment at the Regional Cancer Program, The Heart Institute, and other specialized care.*
   *4.2. Develop and maintain a region-wide database of primary care providers providing palliative care to their own patients and those who are willing to take on new patients with palliative care needs.*

## Focus area 2: Hospice palliative care across a full continuum of care

### *Anticipated Outcomes by 2019:*

- Home and community-based hospice palliative care will be available for more individuals who desire to remain in their communities until the end of their lives.
- A full continuum of hospice palliative care will be available for more individuals, caregivers and families, based on population and service needs. This continuum includes early physician involvement, home/residential care, residential hospice, chronic palliative care, respite care, tertiary hospice palliative care unit, and bereavement.

### *What we need to do to get there:*

1. Enhance in-home palliative care services to include Long Term Care Homes.
   Adequate and appropriate home care is an essential component of hospice care. This care may be provided by CCAC and/or primary care providers. During consultations, several constraints were identified to provide consistent home care across Champlain, but specifically in rural and Aboriginal communities such as: cost and availability of transportation; limited professional services; ability to recruit human resources; and timely access to medications. Most Canadians have indicated they would prefer to receive end-of-life care and to die at home, however this is not the current situation[2].

   *1.1 Engage community members, health and social service providers to develop a strategy to coordinate and enhance in-home palliative care by leveraging community strengths, and enhancing partnerships and technology.*

2. Increase access to day hospice and home visiting services
   Day hospice and hospice-at-home programs are typically volunteer-based and provide the foundation of hospice community services. Day hospice programs provide diversion, support and respite to individuals and their families, as well as, access to care and assessment. Hospice at home programs offer emotional support and practical help to individuals facing a life-threatening illness who are being cared for at home.

   *2.1. Enhance community programming prior to adding residential hospice beds to better assess need and potential impact since these services form the foundation of hospice care.*

3. Increase the number of funded residential hospice beds by 32 across Champlain to reduce the gap by 70% by 2019.
   There are currently seven residential hospices in the Champlain region with a total of 40 adult hospice beds, 8 pediatric hospice beds, and 15 hospice beds for the homeless population. It is estimated 138 beds are required across Champlain to meet the needs of the population. This estimate is based on the Gomez-Batiste recommendation for communities to have 10 hospice palliative care beds per 100 000 inhabitants; of these beds, 1/3 should be acute palliative care beds and 2/3 should be residential hospice beds.

A business case was developed in 2011 to establish a plan to increase residential hospice beds in Ottawa from 9 to 40 beds; implementation of this plan has already begun yet there are still gaps in both Ottawa and surrounding rural communities. Table 1 outlines gaps in availability of acute palliative and residential hospice beds across Champlain and projected increases to reduce this gap. These projections are based on total population, thus may be underestimates as the percentage of individuals older than 65 years of age is increasing. See Appendix B for a more detailed plan.

Establishing and sustaining freestanding residential hospices in communities with less than 100000 residents poses unique challenges. Creative solutions to provide these services in rural communities need to be explored. These plans for increasing residential hospice beds will need to be flexible to align with changing community needs and capacity.

*3.1. Explore options such as the concept of floating beds or other initiatives for rural and remote communities across Champlain.*

***Table 1: Current and Projected Acute Palliative and Residential Hospice Beds in Champlain***

| City/County | Estimated Population (2019)ˆ | Age > 65 yrs | Estimated need* | Number of beds available (2014) | Projected number of beds available (2019) |
|---|---|---|---|---|---|
| Ottawa | 1,019,266 | 161,480 (16%) | 102 | 73 | 96 |
| Eastern Counties | 203,773 | 43,704 (21%) | 20 | 10 | 16 |
| Renfrew | 104,775 | 23,729 (23%) | 10 | 11~ | 11 |
| North Lanark+ | 34,694 | 8,220 (24%) | 4 | 0 | ** |
| North Grenville+ | 15,930 | 3,895 (24%) | 2 | 0 | ** |
| Floating beds ** | | | | 0 | 2-4 |
| **TOTAL++** | **1,376,187** | **238,738 (17%)** | **138** | **94** | **123** |

*ˆ Source: Min. Finance*
*+ Based on Champlain's 2011 portions of Lanark, Leeds and Grenville Counties*
*++ Champlain Total is correct. Summing all geographies overestimated the total due to estimation that are needed for North Lanark and North Grenville*

** based on Gomez-Batiste recommendation: 10 hospice palliative care beds are required per 100 000 inhabitants: 1/3 acute palliative care beds and 2/3 residential hospice*
*** floating beds concept to be assessed*
~ *3 beds currently not receiving LHIN funding, request for these beds to be funded by 2019*

4. Ensure the staffing level for the tertiary Palliative Care Unit is appropriate to meet the complex physical, social and spiritual needs of individuals and their families.

Recent changes in hospital funding have created challenges for palliative care units to provide safe and high quality care. In Champlain, Bruyère Continuing Care is the only health service organization with a palliative care unit with 31 acute palliative care beds. Across Ontario, there is considerable variability in resources and complexity of care required in acute palliative care units, however many face significant financial and staffing barriers including Bruyère Continuing Care[6].

## Focus area 3: Capacity building across care settings

### *Anticipated Outcomes by 2019:*

- Hospice palliative care services will be provided across all care settings (e.g. primary care, home care, hospital) across the Champlain region (e.g. urban, rural, remote).
- Hospice palliative care services will be sustainable and consistent with best practices.
- The hospice palliative care health system will be better integrated by linking sectors and services by common practices, processes, and education.
- Primary, secondary and tertiary levels of palliative care will be accessible 24/7 for more individuals and families.
- Children and their families will have improved transitions from pediatric to adult services.

### *What we need to do to get there:*

1. Implement a public awareness campaign in Champlain about hospice palliative care, advanced care planning, and how to access local services.
   Building greater awareness about the hospice palliative care approach and local services is essential to demystify death and dying and encourage residents to have plans in place for their end of life journey. A communications plan for the Champlain Hospice Palliative Care Program was completed in 2013 that outlines target audiences and strategies for this campaign.

2. Finalize and implement a regional bereavement plan
   Bereavement was consistently highlighted as one of the greatest gaps in the hospice palliative care health system during consultations. Bereavement support is imbedded in a number of community programs, however these support services are not always accessible as they are typically time limited and provided by volunteers. Spiritual support services offered by hospitals, community agencies and faith-based organizations also provide bereavement support and counseling, but likewise have limited capacity and are in high demand.

   Consultations have already begun to develop a comprehensive bereavement plan that: identifies existing services within both public, private and faith-based sectors; proposes models for new and expanded bereavement services; and identifies unique solutions to meet the needs of our diverse population, including Francophones, Aboriginal people, children, and urban, rural and remote populations.

3. Enhance capacity at the primary level to provide palliative care services.
   Primary level palliative care providers (e.g. family physicians, nurse practitioners, cardiologist, oncologists, etc.) require essential palliative care competencies and, at times, may require the support of a specialist-level palliative care consultation team to provide this care. These palliative care consultation teams are intended to provide support through education, consultation and/or shared care, with the aim of building capacity of the primary care provider versus taking over care of the patient. Implementing interprofessional palliative care consultation teams in both community and hospital settings have shown to: improve patient care quality; reduce unnecessary laboratory services; reduce intensive care unit and overall hospital admissions; and reduce health care costs[7-12].

This model has shown to be effective in various Canadian jurisdictions to increase access to and competence of primary care physicians providing palliative care services[13-14]. This model was examined locally in four academic family medicine clinics in Ottawa; by the end of the three year project, most of the physicians in three of the four clinics were providing palliative and end of life care, including doing home visits and caring for their patients in hospice.

3.1. *Evaluate the recently integrated Regional Palliative Consultation Team by 2017 to assess efficacy, adequacy of resources, and potential to expand to further enhance capacity among primary care providers and allied health professionals in both urban and rural regions across Champlain.*

*3.2. Enhance the pediatric 24/7 on-call system to meet the unique needs of children*

4. Coordinate the development and implementation of a regional educational strategy and standards for palliative care education across care settings, across professions, and from school to the workplace.

   Education and continuing professional development are central pillars of a high quality integrated system of hospice palliative care. An education retreat was held in April 2014 with stakeholders. The objective of this retreat was to develop a regional palliative care education strategy, which is underway.

5. Implement and monitor targeted standards and performance indicators.

   System-level accountability, evaluation, monitoring and reporting can be used to optimize the patient experience and quality of care provided to individuals, families and caregivers. Standards for local hospice palliative care providers and organizations were developed over the past two years and approved by The Regional Program Board (see Appendix C). The Regional Program will continue to support implementation and analysis of standards and performance indicators with hospice palliative care providers across Champlain. Specifically, common technical specifications will be drafted; data collection mechanisms and reporting processes will be developed in collaboration with health service providers; and resources developed to reduce the burden of data collection for health service providers. The data and analysis will be shared with stakeholders to inform both regional and organizational planning and quality improvement initiatives.

   *5.1. Identify specific standards, indicators and common technical specifications for inclusion in accountability agreements between hospice palliative care organizations and the LHIN.*

6. Implement the rural framework to build capacity in rural communities.

   Rural and remote communities have unique challenges to build capacity and ensure equitable access to high quality hospice palliative care services. For example, limited transportation, number of health service providers, and access to medications are challenges our local rural communities are currently experiencing. A rural retreat was held in 2012 to draft a rural framework for hospice palliative care; this framework identifies the key elements of a rural program and high priority issues to address (see Appendix D). Creative solutions to provide hospice palliative care services in rural and remote communities need to be further explored to enhance this framework.

7. Leverage existing technology and explore other opportunities to enhance and integrate services across Champlain.

   Technology can be used as a vehicle to build capacity and enhance access to primary, secondary and tertiary palliative care services. For example: a) the CCAC, Hospice Care Ottawa and Bruyère formed a

partnership to implement a central referral and triage system for hospice palliative care beds in Ottawa; and b) the OutCare Foundation supported the development of *TeleLink* an initiative currently being used to link hospice care providers across Champlain with the Division of Palliative Care's weekly journal rounds and academic city-wide rounds.

8. Support the development of volunteer programs
   Volunteers are essential for a high performing hospice palliative care system. Volunteers provide: personal care and support for individuals; respite for caregivers; bereavement support to caregivers and families; facilitation of day hospice programs; administrative support for hospice palliative care agencies; support for fundraising activities; and many other gifts.

   *8.1. Build upon existing community volunteers and infrastructure to enhance volunteer programs across hospice palliative care agencies, integrate services, and ensure a positive volunteer experience.*
   *8.2. Ensure all client care volunteers complete a recognized training program and ongoing education opportunities.*

# 8. Priorities

High priority recommendations are those that are recommended to be addressed early in the Action Plan. These activities will build capacity and form the foundation of our hospice palliative care system, advance current initiatives, leverage opportunities for growth and community strengths, will impact a significant number of individuals across Champlain, and/or address urgent needs.

Medium and lower priority recommendations are those that are required to advance hospice palliative care but may not address an urgent need, require other activities to occur or relationships to be developed in advance, and/or require significant investment or organizational/systemic changes.

The priority level for each recommendation is identified in *Section 9: The Action Plan*.

The high priority recommendations focus on:

- *Increasing the number of residential hospice beds and providing sustainable funding;*
- *Engaging primary care providers and building capacity at the primary level;*
- *Enhancing in-home palliative care services;*
- *Implementing a regional bereavement plan; and*
- *Developing and enhancing volunteer programs.*

# 9. The Action Plan

A priority and projected timeline has been identified for each recommendation. These priorities and timelines outlined in this action plan will inform the development of an annual work plan for The Regional Program and progress will be evaluated on an annual basis.

| FOCUS AREA 1: EQUITABLE ACCESS TO HOSPICE PALLIATIVE CARE | Priority | 2014/15 | 2015/16 | 2016/17 | 2017/18 | 2018/19 |
|---|---|---|---|---|---|---|
| 1. Ensure hospice palliative care services are responsive to the diversity of all residents of Champlain region. This includes: urban, rural and remote populations; Francophone and other culturally/linguistically diverse populations; Aboriginal communities; and other vulnerable populations, such as children, individuals living with disabilities, GLBTQ and the homeless. | Medium | | | | | |
| 1.1. Support the Local Palliative Care Networks in each sub-region across Champlain. These networks engage community members and work collaboratively to identify, develop and implement local solutions and partnerships to ensure hospice palliative care services are responsive to the needs of urban and rural communities. there may be opportunities for these committees to collaborate with emerging provincial initiatives, such as the development of Health Links and Primary Care Networks. | Medium | | | | | |
| 1.2. Enhance access to palliative care services in French by building capacity where needed, leveraging existing resources and integrating the needs of Francophones in the planning of new initiatives/programs. | High | | | | | |
| 1.3. Ensure community-based palliative care is planned in collaboration with Aboriginal people, and mechanisms are in place for this care to be flexible to meet the unique needs of each Aboriginal community. | High | | | | | |
| 2. Provide sustainable funding for residential hospices by increasing funds to a minimum of 80% of total operating costs. | High | | | | | |
| 3. Establish dedicated funds to develop and/or enhance inter-professional palliative care teams in hospitals across Champlain. | Medium | | | | | |

| | | |
|---|---|---|
| 4. Develop a strategy to engage primary care providers to provide palliative care to their own patients. | High |  |
| 4.1. Develop a strategy and support existing initiatives to involve primary care providers early when their patients are receiving treatment at the Regional Cancer Program, The Heart Institute, and other specialized care. | High |  |
| 4.2. Develop and maintain a region-wide database of primary care providers providing palliative care to their own patients and those who are willing to take on new patients with palliative care needs. | Low |  |

| **FOCUS AREA 2: HOSPICE PALLIATIVE CARE ACROSS A CONTINUUM** | **Priority** | **2014/15** | **2015/16** | **2016/17** | **2017/18** | **2018/19** |
|---|---|---|---|---|---|---|
| 1. Enhance in-home palliative care services | High |  | | | | |
| 1.2 Engage community members, health and social service providers to develop a strategy to coordinate and enhance in-home palliative care by leveraging community strengths, and enhancing partnerships and technology. | Medium |  | | | | |
| 2. Increase access to day hospice and home visiting services | Medium |  | | | | |
| 2.1. Enhance community programming prior to adding residential hospice beds to better assess need and potential impact since these services form the foundation of hospice care. | High |  | | | | |
| 3. Increase the number of residential hospice beds by 32 across Champlain to reduce the gap by 70% by 2019. | High |  | | | | |
| 3.1. Assess and pilot the concept of floating hospice beds for rural and remote communities across Champlain. | Medium |  | | | | |
| 4. Enhance the staffing level for the Palliative Care Unit to be appropriate to meet the complex physical, social and spiritual needs of individuals and their families. | Low |  | | | | |

| FOCUS AREA 3: CAPACITY BUILDING ACROSS CARE SETTINGS | Priority | 2014/15 | 2015/16 | 2016/17 | 2017/18 | 2018/19 |
|---|---|---|---|---|---|---|
| 1. Implement a public awareness campaign in Champlain about hospice palliative care, advanced care planning, and how to access local services. | Medium | | | | | |
| 2. Finalize and implement a regional bereavement plan | High | | | | | |
| 3. Enhance capacity at the primary level to provide palliative care services. | Medium | | | | | |
| 3.1. Evaluate the recently integrated Regional Palliative Consultation Team by 2017 to assess efficacy, adequacy of resources, and potential to expand to further enhance capacity among primary care providers and allied health professionals in both urban and rural regions across Champlain. | Medium | | | | | |
| 3.2 Enhance the pediatric 24/7 on-call system to meet the unique needs of children | Medium | | | | | |
| 4. Coordinate the development and implementation of a regional educational strategy and standards for palliative care education across care settings, across professions, and from school to the workplace. | Medium | | | | | |
| 5. Implement and monitor targeted standards and performance indicators. | Low | | | | | |
| 5.1. Identify specific standards, indicators and common technical specifications for inclusion in accountability agreements between hospice palliative care organizations and the LHIN. | Low | | | | | |
| 6. Implement the rural framework to build capacity in rural communities. | Medium | | | | | |
| 7. Leverage existing technology and explore other opportunities to enhance and integrate services across Champlain. | Low | | | | | |
| 8. Support the development of volunteer programs | High | | | | | |
| 8.1. Build upon existing community volunteers and infrastructure to enhance volunteer programs across hospice palliative care agencies, integrate services, and ensure a positive volunteer experience. | High | | | | | |
| 8.2. Offer all volunteers a recognized training program and ongoing education opportunities. | High | | | | | |

# 10. References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# 11. Appendices

## Appendix A: Champlain Hospice Palliative Consultations – Invitees and Participants

### July 19, 2013 – Barry's Bay

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Madawaska Valley Hospice Palliative Care | | Eva Kulas |
| | | Bob Ogilvie |
| | | Lisa Hubers |
| | | Karen Wagner |
| | | Colleen Buch |
| | | Bill Beahen |
| | | Margaret Ogilvie |
| | | Glenda owens |
| | | Toni Lavigne-Conway |
| | | Dr. Jason Malinowski |
| | | |
| Hospice Palliative Care Program | | Josée Charboneau |
| | | Diane Caughey |
| | | Dr. José Pereira |
| | | Jean-François Pagé |
| | | Célestin Abedi |
| | | Peggy Taillon |
| | | |
| LHIN | | Nicole Lafrenière-Davis |
| | | James Fahey |
| | | |
| Saint Francis Memorial Hospital | | Randy Penney |
| | | Jasna Boyd |
| | | |
| Madawaska Communities Circle of Health | | Joanne King |
| | | |
| CCAC | | Penny Sands |

## July 31, 2013 - Renfrew

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Almonte Hub Hospice | Glenda Jones | Glenda Jones |
| | Christine Bois | Christine Bois |
| | | |
| Almonte General Hosp | Mary Wilson Trider | Mary Wilson Trider |
| | | |
| Arnprior & District Hosp | Eric Hanna | |
| | Leah Levesque | Leah Levesque |
| | | |
| Carleton Place & District Hosp | Toni Surko | Toni Surko |
| | | |
| Deep River & District Hosp | Gary Sims | Gary Sims |
| | | |
| Marianhill | Linda M. Tracey | Linda M. Tracey |
| | | |
| Pembroke Regional Hosp | Pierre Noel | |
| | Sabine Mersmann | Sabine Mersmann |
| | | |
| Renfrew Hospice | Diane Caughey | Diane Caughey |
| | | |
| Renfrew Victoria Hosp | Randy V. Penney | |
| | | |
| Bruyère - Pain & Symptom Management | Erin McCabe | Erin McCabe |

## August 7, 2013 - Cornwall

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Bayshore Home Health | Leslie Marvell | Leslie Marvell |
| | | |
| Bruyère Contininuing Care | Danielle Sinden | Danielle Sinden |
| | | |
| Canadian Red Cross Society | Colette Lavictoire | Colette Lavictoire |
| | | |
| Carefor | Ghislaine Lalonde | |
| | Jason Samson | Jason Samson |
| CCAC | Richard Thompson | Richard Thompson |

| | | |
|---|---|---|
| | Lucie Houle | |
| Centre Marysabel Center | Louise Beaupré | |
| | Marianne Vancaemelbeke | Marianne Vancaemelbeke |
| Centre de soins palliatifs Hospice Simons | Ingrid Aartman | |
| | | |
| Cornwall Hospice | Dr. Mary Jane Randlett | Dr. Mary Jane Randlett |
| | Maria Badek | Maria Badek |
| | Dr. Clara Leigh | Dr. Clara Leigh |
| Cornwall Community Hospital | JoAnn Tessier | |
| | Marlene Power | Marlene Power |
| | | |
| Dundas County Hospice | Bea VanGilst | Bea VanGilst |
| | | |
| Glengarry NP Led Clinic | Penelope Smith | Penelope Smith |
| | | |
| Glen-Stor-Dun Lodge | Linda Giesel | |
| | Mary Johnson | |
| | Norm Quenneville | |
| Hawkesbury & District General Hospital | Sylvie Lefebvre | Sylvie Lefebvre |
| | Dr. André Borduas | |
| Hopital Glengarry Memorial | Shelley Coleman | |
| | | |
| LHIN | James Fahey | |
| | | |
| Maxville Manor | Sue MacDonald | Sue MacDonald |
| | | |
| Mohawk Council of Akwesasne | Frances Renaud | Frances Renaud |
| | Sarah Thompson | Sarah Thompson |
| Le Réseau | Jean-François Pagé | |
| | | |
| | | |
| Saint Elizabeth Health Care | Kerri Schnobb | Kerri Schnobb |
| | Barbara Knotes | |
| Seaway Valley CHC | Debbie St.John-de-Wit | |
| | | |
| St. Joseph Continiuning Care | Martina Anderegg | Martina Anderegg |
| | | |
| Winchester District Memorial Hospital | Lynn Hall | |

| | |
|---|---|
| Woodland Villa | Michael Rasenberg |
| | |
| Parisian Manor | Andrew Lauzon |
| | |

## August 19, 2013 - Kemptville

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Beth Donovan Hospice | Dawn Rodger | Dawn Rodger |
| | Sue Walker | Sue Walker |
| | Chris McBean | Chris McBean |
| Hospice Care Ottawa | Lisa Sullivan | Lisa Sullivan |
| | | |
| Kemptville Hospital | Catherine Van Vliet | |
| | | |
| LHIN | James Fahey | James Fahey |
| | | |
| Local Physicians | | |

## September 5, 2013 - Hawkesbury

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Hawkesbury & District General Hosp | Sylvie Lefebvre | Sylvie Lefebvre |
| | Dr. Renée Arnold | Renée Arnold |
| | Dr. André Borduas | André Borduas |
| | Marc Leboutillier | Marc Leboutillier |
| | Diane Drapeau | |
| | Suzanne Sauvé | |
| | | |
| Carefor | | Jason Samson |
| | | |
| Centre Marysabel Center | Louise Beaupré | |
| | | Marianne Vancaemelbeke |
| Cornwall Hospice | Maria Badek | Maria Badek |
| | | |
| Centre de soins palliatifs Hospice Simons | Ingrid Aartman | Ingrid Aartman |
| | | |
| CCAC | Lucie Houle | Lucie Houle |

| | | |
|---|---|---|
| | Richard Thompson | Pierre D'Aoust |
| Réseau des services de santé en francais | | Jean-François Pagé |

## October 25, 2013 - Akwesasne

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Bayshore Home Health | Leslie Marvell | |
| | | |
| Mohawk Council of Akwesasne | Frances Renaud | Frances Renaud |
| | Sarah Thompson | Sarah Thompson |
| | Joelle Regnier | Joelle Regnier |
| | | Rita Busat/Peggy Taillon |

## October 31, 2013 - Ottawa

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Bruyère Continuing Care | Dr. José Pereira | Dr. José Pereira |
| | Marc Guevremont | |
| | Peter Lawlor | |
| | Colleen Cuddy | |
| | Teresa M. Lee | |
| Montfort Hospital | Anne Roberts | Anne Roberts |
| | Dr. Bernard Leduc | Therese Antoun |
| | | |
| LHIN | James Fahey | |
| | Chantale LeClerc | |
| | | |
| The Ottawa Hospital | Lynn Kachuik | Dr. José Pereira |
| | Jim Worthington | |
| | Paula Doering | |
| | Edward Fitzgibbon | |
| Queensway Carleton Hospital | Alice Retik | Alice Retik |
| | | |
| | Andrew Knight | |

## November 6, 2013 - Renfrew

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Almonte Hub Hospice | Christine Bois | Christine Bois |
| | Wendy Powell | |
| | | |

| | | |
|---|---|---|
| Almonte General Hosp | Mary Wilson Trider | Mary Wilson Trider |
| | | |
| Arnprior & District Hosp | Eric Hanna | |
| | Leah Levesque | Leah Levesque |
| | | |
| Carleton Place & District Hosp | Toni Surko | Toni Surko |
| | | |
| Deep River & District Hosp | Gary Sims | |
| | | |
| Marianhill | Linda M. Tracey | Linda M. Tracey |
| | | |
| Pembroke Regional Hosp | Pierre Noel | |
| | Sabine Mersmann | |
| | | |
| Renfrew Hospice | Diane Caughey | Diane Caughey |
| | | |
| Renfrew Victoria Hosp | Randy V. Penney | |
| | | |
| Bruyère - Pain & Symptom Management | Erin McCabe | Erin McCabe |

## November 12, 2013 - Ottawa

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Bruyère Continuing Care | José Pereira | José Pereira |
| | Marc Guevremont | |
| | Peter Lawlor | |
| | Teresa M. Lee | Teresa M. Lee |
| Montfort Hospital | Anne Roberts | Anne Roberts |
| | Therese Antoun | Therese Antoun |
| LHIN | James Fahey | |
| | | |
| The Ottawa Hospital | Lynn Kachuik | José Pereira |
| | Jim Worthington | Lynn Kachuik |
| | Paula Doering | |
| | Edward Fitzgibbon | |
| Queensway Carleton Hospital | Alice Retik | |
| | Andrew Knight | |
| | | |

## November 13, 2013 - Arnprior

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|

| | | |
|---|---|---|
| Algonquins of Pikwàknagàn First Nation | Peggy Dick | Peggy Dick |
| | Maureen Kauffeldt | Maureen Kaufeldt |

## November 15, 2013 - Hawkesbury

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Hawkesbury & District General Hosp | Sylvie Lefebvre | Sylvie Lefebvre |
| | Dr. Renée Arnold | |
| | Dr. André Borduas | Dr. André Borduas |
| | Marc Leboutiller | |
| | Marielle Heuvelmans | |
| Bayshore Home Health | Leslie Marvell | |
| | | |
| Carefor | Donna Tinker | Donna Tinker |
| | | |
| Centre Marysabel Center | Louise Beaupré | Louise Beaupré |
| | Marianne Vancaemelbeke | Marianne Vancaemelbeke |
| | Pierre Paul Lalonde | Pierre Paul Lalonde |
| Cornwall Hospice | Maria Badek | Maria Badek |
| | | |
| Centre de soins palliatifs Hospice Simons | Ingrid Aartman | Ingrid Aartman |
| | | |
| CCAC | Lucie Houle | |
| | Glenda Owens | Glenda Owens |
| | Pierre D'Aoust | Pierre D'Aoust |
| Réseau des services de santé en francais | Jean-François Pagé | |
| | | |

## November 20 – Dec 20, 2013 - Ottawa

| ORGANIZATION | INVITEE | PARTICIPANTS |
|---|---|---|
| Hospice Care Ottawa | Lisa Sullivan | Lisa Sullivan |
| | | |
| Ottawa Inner City Health Inc. | Wendy Muckle | Wendy Muckle |
| | | |
| HPCO | Rick Firth | Rick Firth |
| | | |
| Roger's House | Lloyd Cowin | Lloyd Cowin |

| | | |
|---|---|---|
| Réseau des services de santé en francais | Jean-François Pagé | Jean-François Pagé |

## Appendix B:

### Detailed Current and Projected Acute Palliative and Residential Hospice Beds in Champlain

| City/County | Estimated Population (2019)ˆ | Age 65+ years | Estimated need* | Number of beds available (2014) | Projected number of beds available (2019) |
|---|---|---|---|---|---|
| **Ottawa** | 1,019,266 | 161,480 (16%) | **102** | **73** | **96** |
| Palliative Care Unit (Bruyère) | | | | 31 | 31 |
| Roger's House (children) | | | | 8 | 10 |
| Hospice Care Ottawa | | | | 19 | 40 |
| Mission Ottawa (homeless) | | | | 15 | 15 |
| **Stormont-Dundas-Glengarry** | 203,773 | 43,704 (21%) | **20** | **10** | **16** |
| Hospice Cornwall | | | | 10 | 10 |
| **Prescott-Russell** | | | | | |
| Hawkesbury | | | | 0 | 6 |
| **Renfrew** | 104,775 | 23,729 (23%) | **10** | **11** | **11** |
| Hospice Renfrew | | | | 6 | 6 |
| Hospice Madawaska | | | | 2 | 2 |
| Marianhill | | | | 3~ | 3 |
| **North Lanark**+ | 34,694 | 8,220 (24%) | **4** | **0** | ** |
| **North Grenville**+ | 15,930 | 3,895 (24%) | **2** | **0** | ** |
| **Floating beds ** ** | | | | **0** | **2-4** |
| **TOTAL**++ | **1,376,187** | **238,738 (17%)** | **138** | **94** | **123** |

ˆ *Source: Min. Finance*
+ *Based on Champlain's 2011 portions of Lanark, Leeds and Grenville Counties*
++ *Champlain Total is correct. Summing all geographies overestimated the total due to estimation that are needed for North Lanark and North Grenville*

** based on Gomez-Batiste recommendation: for every 100 000 inhabitants, 10 hospice palliative care beds are required: 1/3 acute palliative care beds and 2/3 residential hospice*
*** floating beds concept to be assessed*
*~ Currently not receiving LHIN funding, request for these beds to be funded by 2019*

## Appendix C: Champlain Hospice Palliative Care Indicators

**22 Priority Indicators - Master List - September 30, 2013**

KEY: data sources= all actual/potential sources of data collected

settings/providers = all actual/potential location/provider of care

| | Shared by: | Indicator Category | Quality Indicator/ Measure Name | Numerator / Descriptive Statistic | Denominator | Description of Data Sources | Yrs of Data Available | Any Other Relevant Information | Quality Improvement | Accountability | Research |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of CA pts dying in an acute care hospital | # cancer patients dying in an acute care hospital | total # cancer deaths | CIHI/CCO | annual | provincial reporting is 3 years old...may need to be in SharePoint System (Regional Program) | x | | |
| 2 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of non malignant end stage disease (heart, lung) pts dying in an acute care hospital | # non malignant end stage disease (heart, lung) pts dying in an acute care hospital | total # of end stage deaths in acute care in the region | CIHI | annual | provincial reporting is 3 years old...may need to be in SharePoint System (Regional Program) - may expand to other end stage diseases | x | | |
| 3 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of CA pts dying in various settings | # cancer patients dying in specific settings | total # cancer deaths in various settings | data from all patients and all settings in region, cancer registry, CCAC | annual | specific settings as per locations | x | | |
| 4 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of RNs in Nursing Agencies providing HPC who have rec'd Pallium LEAP training | # RNs in Nursing Agencies providing HPC who rec'd Pallium LEAP training | total # RNs in Nursing Agencies providing HPC | all Nursing Agencies, CCAC | annual | if nurse has CNA certification, report this as having LEAP training (5 year cycle) | | x | |
| 5 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of RPNs in Nursing Agencies providing HPC who have rec'd Pallium LEAP training | # RPNs in Nursing Agencies providing HPC who rec'd Pallium LEAP training | total # RPNs in Nursing Agencies providing HPC | all Nursing Agencies, CCAC | annual | 5 year cycle | | x | |
| 6 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of HPC volunteers who have rec'd standardized training | # of HPC volunteers who have rec'd standardized training | total # of HPC volunteers | all settings in all sectors that have HPC volunteers, CCAC | annual | | | x | |
| 7 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | % of pts receiving Palliative home care with EDITH protocol in place | # of pts receiving Palliative home care with EDITH protocol in place | total # of pts receiving Palliative home care | CCAC | annual | Local Indicator | x | | |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 8 | *Champlain Regional Hospice Palliative Care Program* | **Capacity** | # of referrals to different HPC services: Acute Care / Hospital HPC service, Cancer Center HPC service, Community Consult Service / NPs, Hospice and PCU and referred from where | # of referrals to different HPC services: Acute Care / Hospital HPC service, Cancer Center HPC service, Community Consult Service / NPs, Hospice and PCU and referred from where | | Survey, CRT | annual | tracking trends | x | | |
| 9 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % dying pts with DNR in place at the time of referral to the HPC team at CCAC, hospital consult services, CA Clinic outpatient, Consult Team / NPs | # patients with a DNR in place at time of referral to the HPC team at CCAC, hospital consult services, CA Clinic outpatient, Consult Team / NPs | total # of referrals to the HPC team at CCAC, hospital consult services, CA Clinic outpatient, Consult Team / NPs | CCAC (also from TOH and SharePoint in future) | 2x/year | include all palliative clients not only HPC team. % of physician and nursing staff receiving training in basic and end of life communication skills , ACP and goals of care future indicator of choice | x | | |
| 10 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % of time a CCAC palliative patient was cared for at home in the last 4 weeks of life | # of days cared for at home over the last 4 weeks of life | 30 days (last 4 weeks) | CCAC, others | annual | use retrospective chart audit, a good indicator but difficult to collect; CCAC collects data on patient dying in place of choice | x | | |
| 11 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % pts referred to CCAC HPC in last 2 weeks of life | # patients referred to CCAC HPC in the last 2 weeks of life | total # patients referred to CCAC HPC | CCAC | 2x/year | not all patients in the last 2 weeks of life were referred to CCAC HPC | | x | |
| 12 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % of CA pts who visited the ED in the last 2 weeks of life | # of CA pts who visited the ED in the last 2 weeks of life | total # CA pts who visited the ED | CCO | annual | 2-3 year old data; trending may be possible | x | | |
| 13 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % of non malignant end stage disease (heart, lung) pts who visited the ED in the last 2 weeks of life | # non malignant end stage disease (heart, lung) pts who visited the ED in the last 2 weeks of life | total # of non malignant end stage (heart,lung) disease pts who visited the ED | CIHI | annual | 2-3 year old data; trending may be possible-- focus on heart, lung then broaden to include other end stage diseases | x | | |
| 14 | *Champlain Regional Hospice Palliative Care Program* | **Access** | mean, median, range and discharge rate of HPC patients in hospice and PCU | mean, median, range and discharge rate of HPC patients in hospice and PCU | | Providers | 2x/year | this will reflect total number of patients days | x | | |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 15 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % of Family physicians (FP) in community referring to Community Consult Team / NPs | total # of FP in community referring to Community Consult Team /NPs (urban vs rural) | total # of FP in community | Referral Database Community Consult Team / NPs | annual | Acute Care setting added as FPs provide coverage in Community Hospital | | X | |
| 16 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % of FHTs/ FHOs/ FHGs/ FHNs, CHCs delivering EOL care | # of FHTs/ FHOs/ FHGs/ FHNs, CHCs delivering EOL care | total # of FHTs/ FHOs/ FHGs/ FHNs, CHCs | Survey ICIS Provincial | annual | Provide 24 /7 access home visits, phone calls | X | | |
| 17 | *Champlain Regional Hospice Palliative Care Program* | **Access** | % of LTC facilities with formal EOL care strategy in place | # LTC facilities with formal EOL care strategy in place | total # LTC facilities | Survey | annual | future will be looking at retirement homes Pts with high risk of dying - goals of care discussion | X | | |
| 18 | *Champlain Regional Hospice Palliative Care Program* | **Coordination** | % of transfers to hospice/PCU that went through CRT | # of transfers to hospice/PCU that went through CRT | total # of transfers to hospice/PCU | Survey | 2x/year | Local indicator | X | | |
| 19 | *Champlain Regional Hospice Palliative Care Program* | **Coordination** | median time in days prior to death that pts are referred to CCAC for home care | median time in days prior to death that pts are referred to CCAC for home care | | CCAC, CCO | 2x/year | emphasis is on time | X | | |
| 20 | *Champlain Regional Hospice Palliative Care Program* | **Quality/ Outcomes** | mean, median and total number of hospital days palliative patients spent waiting for a PCU or hospice bed | mean, median and total number of hospital days palliative patients spent waiting for a PCU or hospice bed | | hospice and PCU | 2x/year | | X | | |
| 21 | *Champlain Regional Hospice Palliative Care Program* | **Quality/ Outcomes** | Average # days patient waited from triage application receipt to admission to PCU or hospice | Average # days patient waited from triage application receipt to admission to PCU or hospice | | CRT | 2x/year | | | X | |
| 22 | *Champlain Regional Hospice Palliative Care Program* | **Quality/ Outcomes** | Patient and family satisfaction with HPC for patients being cared for at home, PCU, hospice or hospital | Patient and family satisfaction with HPC for patients being cared for at home, PCU, hospice or hospital | | Pts Survey in all settings | every 2 years | 1. Should you have been referred sooner?<br>2.Were you satisfied with the care?<br>3.Would you recommend this service? | | X | |

## Appendix D: The Rural Hospice Palliative Care Program Framework

### CHAMPLAIN REGIONAL HOSPICE PALLIATIVE CARE PROGRAM

### RURAL HOSPICE PALLIATIVE CARE PROGRAM FRAMEWORK

**October 2013**

Based on the work done at the Champlain HPC Program's Rural Retreat in 2012 (with input from "best" practices for rural programs across the country), a literature review, work done in the Madawaska Valley and other rural communities.

For the purpose of this framework, we recognize that within rural communities there are "larger" towns of 10,000 or more inhabitants which have urban features, "smaller" towns and villages of less than 10,000 inhabitants, "rural areas" which are primarily farming communities and "remote communities" with very sparse population densities.

#### Goal of a Rural Hospice Palliative Care Framework

- Ensure that key elements are addressed and/or included when rural-based Hospice Palliative Care Programs are developed in the Champlain Region;
- Ensure standardization of Rural models across the Champlain Region, while allowing some flexibility to address local unique circumstances;
- Ensure success and sustainability of rural-based HPC Programs in the Champlain Region;
- Apply best evidence and best practices from the literature and from other Canadian and International jurisdictions with respect to establishing rural-based HPC Programs.

#### Guiding Principles

The Champlain Regional Hospice Palliative Care Program:

- Recognizes that key elements are required to ensure appropriateness and success of rural-based Hospice Palliative Care access;
- Recognizes that rural and isolated areas within the Champlain LHIN region may have specific unique circumstances that require some flexibility need to be recognized;
- Rural HPC care programs, as with urban-based programs, need to be effective, sustainable, efficient, high quality and optimize local and existing resources;
- Development of HPC programs take time (usually several years) and are undertaken in phases, with high priority elements addressed in the earlier phases.

#### Champlain Regional HPC Program's "Rural HPC Framework"

- Proposals in areas in the region wishing to implement HPC programs in rural areas should address each of the key elements. It is not expected that all elements will be implemented from the outset, but the intention should be to integrate them over time (approximately 3 to 5 years).
- The HIGH PRIORITY elements should be implemented in the early phases.

- The First Phase in all the projects should be the establishment of a Local HPC Team to plan, implement and monitor the HPC program locally (using Dr. Marie Lou Kelley's Rural Model).
    - This team should include volunteers, health professionals (includes nurses, doctors, social workers and other allied health professionals), health care administrators, community leaders and other stakeholders.

## Key elements of a Rural-Based HPC Program in the Champlain Region

1. **Local Hospice Palliative Care Implementation Team** (HIGH PRIORITY)
2. **Volunteer Program** (HIGH PRIORITY)
3. **Ensure Access to Primary, Secondary and Tertiary Level of Palliative Care 24/7** (HIGH PRIORITY)
4. **Education Strategy for local Health Care Providers** (e.g. physicians, nurses, SWs, pharmacists, etc) (HIGH PRIORITY)
5. **Home Care Services** (HIGH PRIORITY)
6. **Hospice community programs**
7. **Use of standardized symptom and needs screening and assessment**
8. **Inpatient care model that is population and resource based**
9. **Public Awareness campaign** (including Advance Care Planning)
10. **Use of E-Health technologies to enhance access to care**
11. **Access to appropriate medications and supplies**
12. **Medical equipment loan program**
13. **Standards and Performance Indicators**

## Element 1: Local Hospice Palliative Care Implementation Team

- The role of the Local Hospice Palliative Care Team (Local Team) is to develop the proposal and implement, monitor and maintain local HPC services. Use Dr. Mary Lou Kelley's Rural Model of local capacity building
- The Local Palliative Care Team (LPCT) should include:
    - HPC champions of clinicians, public members, administrators, volunteers, and other stakeholders.
    - A Family physician champion
    - CCAC care coordinator
    - Community leader(s)
- The Local HPC Team is to work closely with the Champlain Regional Hospice Palliative Care Program and LHIN to develop the proposal.

## Element 2: Volunteer Program

- Volunteers constitute a key component of HPC programs.
- The Plan should include resources to provide Logistical Support and Coordination of HPC volunteers
- The Plan must include a recognized Training Program for local volunteers.
- The volunteer program assists or supports hospice-in-the-community services, such as day-hospice and hospice-at-home programs, as well as any hospice-type residential program.

## Element 3: Ensure Access to Primary, Secondary and Tertiary Level of Palliative Care 24/7

- It is recognized that patients and families experience many different needs across the illness trajectory; some of them uncomplicated while others may be complex.
- To adequately meet these needs, three levels of services is required;
  - A) **Primary Level** (e.g. provided by family physicians and generalist nurses)
  - B) **Secondary Level** (health care providers with additional competencies and experience to address more complicated cases)
  - C) **Tertiary Level** (specialists in palliative care to provide clinical and education support to Secondary and Primary-level providers).
- The Champlain HPC Program has described these various levels and the competencies required in each in its Primary, Secondary and Tertiary Model document of the Standards Committee (please refer to that document).

- **Primary level**
  - As many as possible of the family physicians in the area should provide palliative care to their patients and serve as the Most Responsible Physician (MRP)
  - The "Ask the Question?" approach ("Will I be surprised if this patient dies in the next 6 to 12 months?") should be activated in all family practice medicine clinics to identify patients who could benefit from a palliative care approach (sometimes alongside efforts to control the disease.
  - The goal of this is to ensure earlier goals of care discussions, advance care directive discussions and symptom assessment & management.
  - Family Medicine clinics should be encouraged to maintain a "Palliative Care Registry" of "palliative" patients (defined using the "surprise question" above) so that at any given time a list can be generated of patients requiring HPC services.
    - This will require some adaptation of their charting processes (including EMRs).

- **Secondary level**
  - Requires physicians and/or nurses (NP or APN) with additional training and experience in palliative care.
  - The role is to support local colleagues in providing HPC by providing consultation support without taking over the care of the patients as MRP in most cases.
  - Training: Ideally, a physician or NP with specialist level training (one year residency in the case of MDs and HPC Certification through the Canadian Nursing Association for nurses). However, in the absence of that, then someone with more training than basic level- LEAP Plus at least 4 months training program (that includes some clinical rotation time with the regional specialist level team and coaching by that team) and with ongoing support from the Palliative Consultation Service (PACS/PPSMCS), will suffice.
  - The person(s) should participate regularly in regional HPC continuing professional development activities such as the Academic City Wide and Journal Club Rounds (via Telelink).
  - Ideally, these persons should be remunerated using a AFP or salary model so that they are able to provide clinical support (without being driven to a fee for service model), education and quality improvement activities) in their region.

- **Tertiary level**
  - To be provided by the Division of Palliative Care (out of Bruyère Continuing Care and TOH) and by the Nurse Practitioners and APN of PACS/PPSMCS.

- Clinical Support
    - Regular team meetings, using Telelink, between the local HPC providers and the PACS team to review difficult cases (team consultation).
    - Just-in-time availability of PACS to support colleagues in the rural area.
- Education Support
    - The specialist team should participate in any education development program geared towards doctors, nurses and pharmacists in the region.
- Quality Improvement Support
    - The specialist team should provide input on quality improvement programs or project in the region, particularly when they relate to clinical care.

**Element 4: Education Strategy for local Health Care Providers**

- The Champlain Regional HPC Program recognizes the importance of educating local health care professionals on the basics of providing HPC and to support these professionals with specialist level services should they require them.
- The rural HPC program should include a strategy for continuing professional development (CPD) and continuing medical education (CME) for local physicians, nurses, pharmacists, SW, etc on HPC.
- This is to include delivering Pallium LEAP courses locally and linking up local health care professionals to the Bruyère Thursday Evening Series and any other HPC-related CPD activities.

**Element 5: Home Care Services**

- Adequate and appropriate home care is a key component of any HPC program.
- Home Care services should be optimized.
- CCAC Care Managers and Nurse Agency nurses should all receive Pallium LEAP training in HPC.
- The patient's own family physician should be the MRP and should be able to provide, for those patients in the terminal phase, home visits and on-call support, as well as prompt availability to nurses when advice is required. Should this not be forthcoming, the patient and family should approach the physician to change to another physician.
- The Champlain Regional Program also recognizes that there are some limitations to putting in place indefinite 24/7 home services (due to lack of personnel, funding, etc). In these situations, an alternative setting of care, such as a local hospital, or residential hospice may be required.
- Family caregivers are an integral component of the Home Care Team, alongside the CCAC Care Manager, Agency Nurse and family physician.

**Element 6: Hospice community programs**

- Volunteer-led programs to provide community outreach, Hospice -Day and Hospice at-home programs should be in place as a cornerstone of the program. These programs may also include a Bereavement Support Program
- Rural residential hospice teams (eg Renfrew Hospice, Cornwall Hospice) can serve as hubs for these services.

**Element 7: Use of standardized symptom and needs screening and assessment**

- The following approaches and screening and assessment instruments should be used in routine practice:

  - Edmonton Symptom Assessment Scales (ESAS)
    - To screen for and assess key physical and emotional symptoms
  - Palliative Performance Scale (PPS)
    - To assess functional status, which guides prognosticating and decision-making
  - Confusion Assessment Method (CAM)
    - To screen for and diagnose delirium.
  - Richmond Agitation Sedation Scale for Palliative Care (RASS-Pal)
    - To assesses levels of agitation and of sedation
- The following approaches should be used in routine practice:
  - Ask the "Surprise question" (and mortality risk indicators) in regular practice to identify patients who could benefit from a palliative care approach earlier
  - Palliative Alerts
    - To guide implementation of HPC resources and services
  - "Speak Up" CHPCA Program on Advance Care Planning

### Element 8: Inpatient care model that is population and resource based

- It is recognized that generally free-standing hospices with less than 9 to 10 beds are challenging to sustain.. A population of at least 80 000 to 100 000 is required to justify a hospice. The Champlain framework recognizes the need for residential or in-patients care for some patients and recognize also the realities of rural areas. When larger communities covering a rural population of 60,000-80,000 inhabitants, a hospice of 6 to 10 beds may be considered. Alternatively, another model particularly for smaller communities would be some 4 to 6 beds in an existing healthcare facility.
- There is also the "Madawaska model" based on geographic realities that may make it difficult at times to care for non-ambulatory patients who are not complex at home. A small number of flexible beds in an existing facility (e.g. LTC or hospital) with care provided by CCAC and volunteers. However, if a patient's needs increase to the point that CCAC is no longer able to provide the services in the "chronic care volunteer hospice", the patient should be admitted to the local hospital if home is not an option.
  - Patients with high acuity-level needs requiring sustained 24/7 in-patient care should be admitted to the local hospital.
- Rural Hospice programs should take in considerations the Hospice Palliative Care Ontario standards.

### Element 9: Public Awareness campaign: What is Palliative Care and Advance Care Planning?

- A strategy should be developed for a public awareness campaign in the region.
- This should include"
  - Advance Care Planning campaign (using the *Speak Up* materials)
  - What is Hospice Palliative Care campaign (The Regional Program will prepare some messaging material for that)
  - The campaign should include exposure in the local media and events, including reaching out to local church communities to assist in making the public aware.

### Element 10: Use of E-Health technologies to enhance access to care

- Two Health Information Technologies should be considered to enhance rural access to the different level of care:

1. Telemedicine using Telelink:

  - Local rural teams to use Telelink to link up with the Division of Palliative Care's weekly journal rounds and twice-monthly academic city wide rounds

2. Videophone technology:
   - The Champlain HPC program is collaborating with CISCO to explore the use of videophones to connect patients from their homes with their CCAC case managers and nurses.

### Element 11: Access to appropriate medications and supplies

- An "Emergency Kit" with essential medications and supplies should be placed in the homes of home-care patients with PPS scores of 30% or less. In larger urban areas, a process to rapidly access emergency medications and supplies should be implemented (instead of Emergency kits)- this would require rapid 24/7 access to a local pharmacy who could provide these.
  - The PPSCMS has developed a list of essential medications and supplies.
- There should be a plan to provide access to pumps and hypodermoclysis supplies locally.
  - This requires close collaboration with the local hospital and/or a local pharmacy

### Element 12: Medical equipment loan program

- There should be a program/process in place locally to provide hospital beds and other equipment such as wheelchairs, particularly those not covered by CCAC Services.

### Element 13: Standards and Performance Indicators

- The program will identify standards for its various programs/services.
  - Those of the Champlain Regional Program that apply should be included, plus any additional ones identified locally.
- The program will identify performance indicators to audit services.
  - Those of the Champlain Regional Program that apply should be included, plus any additional ones identified locally.
- There will be a mechanism in place to collect data related to the performance indicators.