

CHAMPLAIN REGIONAL HOSPICE PALLIATIVE CARE PROGRAM PLAN

**BY THE PLANNING COUNCIL OF THE
CHAMPLAIN HOSPICE PALLIATIVE AND END
OF LIFE NETWORK**

MAY 19TH, 2010

ACKNOWLEDGEMENTS

We would like to thank the many people who contributed to the development of this plan. In particular, our sincere appreciation to the members of numerous project working groups who spent a considerable amount of time and energy while working within tight timeframes to develop and analyze their deliverables and to the many individuals who reviewed the document and provided feedback as part of our stakeholder engagement process.

The information provided has been invaluable in the development of the current draft plan and will continue to inform the establishment of a successful Regional Hospice Palliative Care Program in Champlain.

A special thanks to the individuals, caregivers and volunteers who gracefully shared their thoughts to enhance the Plan.

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EXECUTIVE SUMMARY

The main objective of the Champlain’s Local Health Integration Network’s (LHIN) is to coordinate health services to ensure that people receive the care they need and deserve in a timely way. In keeping with this goal, the LHIN has recognized the need for enhanced coordination and planning of hospice palliative care (HPC) services in this region. Moreover, there is a need to reduce the number of inappropriate emergency room visits by individuals requiring palliative care, and ultimately, reduce the number of deaths that occur in acute care settings and thereby increasing the number of palliative deaths at home and in the community.

To respond to these issues, the Champlain LHIN has given the Champlain Hospice Palliative and End of Life Care Network (CHPEOLCN) the mandate to develop a comprehensive and integrated hospice palliative care service plan for the region. A Retreat was held in April 2009 where important system components to support regional integration were identified. These are listed in the table below.

Key Regional HPC Program Elements	
1.	A Common Region Wide Vision and Mission for Hospice Palliative Care in Champlain <i>....so that individuals and their families are working with all providers toward the same goals</i>
2.	A governance/leadership structure to provide direction, manage, and address issues of accountability and sustainability for the new Regional HPC Program as well as conduct strategic planning and ongoing community engagement <i>..... to be accountable for a Program that meets the needs of individuals and their families</i>
3.	Access to information and services <i>.... so individuals, their families, care providers and volunteers have somewhere to go to access information and services</i>
4.	An adequately resourced system <i>... to ensure appropriate services are available to individuals and their families when and where they are needed</i>
5.	Evidence-based care and best practices <i>....so services delivered to individuals and their families are based on research, where available, and are the most effective known</i>
6.	Common reporting/data collection and performance indicators <i>....to identify through evaluation that the Program is meeting the needs of individuals and their families</i>

7. A strong and well supported primary care service delivery model <i>....to support, assist and encourage family physicians and others in providing HPC services to individuals with progressive, incurable illness and their families</i>
8. Standards and competencies <i>..... to ensure individuals and their families have access to quality care across the system</i>
9. Education, knowledge transfer and research <i>.... to ensure everyone involved in HPC, including individuals, their families, service providers and volunteers, has access to a standardized education program and resources to expand their knowledge and to assist in ensuring the application of evidence-based and best practices.</i>

An in-depth planning process was then conducted involving the formation of a number of working groups with representation from service providers and other individuals from across Champlain. The outcomes and recommendations from the working groups were reviewed in detail, organized around the key elements and consolidated to form the draft plan for a Regional HPC Program in Champlain.

Recommendations

The Plan put forward in this document is framed around three foundational recommendations:

- a. The establishment of a **Regional Hospice Palliative Care (HPC) Program** for Champlain to ensure an integrated and coordinated delivery of palliative care services strongly supporting the involvement of primary health care in HPC.
- b. The formation of a **Leadership Committee** to oversee the program.
- c. The establishment of **formal agreements** with HPC providers to support the objectives of the Program, to incorporate service delivery standards and competencies as well as to establish performance indicators for evaluation and program planning.

..... and the following priority recommendations which will form the initial work plan of the Leadership Committee to address the most pressing system issues and gaps (not ranked):

- d. Implement a regional HPC program with a strong primary care basis supported by secondary and tertiary level palliative care expertise

- e. Develop service delivery standards and competencies that will be incorporated into agreements with service providers
- f. Establish specific system and provider performance measures for ongoing system planning, monitoring and surveillance to be incorporated into accountability agreements with the Champlain LHIN
- g. Recommend funding allocation and realignment of resources to the Champlain LHIN following thorough analysis of current resources and system gaps
- h. Develop a regional HPC bed plan which will include a realignment of resources from the acute care sector
- i. Develop and implement a strategy for enhancing HPC in LTC Homes
- j. Establish a comprehensive, accessible information system initially focused on HPC related services for individuals, family members and professionals to assist with system navigation
- k. Establish and communicate clear criteria for access to HPC services
- l. Expand the use of e-health/tele-health and other technologies to support care delivery and education, particularly in rural and remote regions
- m. Develop a standardized regional strategy for HPC education for all stakeholders
- n. Develop strategies to ensure there is adequate access to secondary and tertiary consultation teams in the region's hospital, hospices, LTC Homes and the community.

Summary

The Regional HPC Program Plan presented in this document provides an innovative approach to moving toward an integrated and coordinated service delivery system for palliative care services in Champlain. It represents the collaboration and contribution of many individuals. Once implemented, the recommendations presented in this document will have a significant impact on the quality and accessibility of HPC services to the residents of Champlain and at the same time, will make a significant contribution to addressing the current fiscal and utilization pressures of the health care system.

BACKGROUND DOCUMENT

WHAT IS HOSPICE PALLIATIVE CARE?

INTRODUCTION

Palliative care is defined by the Canadian Hospice and Palliative Care Association (CHPCA) as “whole-person health care that aims to relieve suffering and improve the quality of living and dying”. It is care that is applicable at various stages of a person’s journey, from the time of diagnosis of the life threatening illness, to the terminal phase (last days and weeks of life). It extends beyond the death of the person by providing grief and bereavement care to loved ones. It is not mutually exclusive with treatments to control the disease. In other words, an individual may be receiving chemotherapy to control cancer or heart medications to control severe heart failure but still benefit from palliation of symptoms to improve quality of life as well as care to address psychological and spiritual distress. Early discussions about advance directives and end of life care are an integral component of this approach.

The World Health Organization (WHO) in the 1980’s had originally defined palliative care as being applicable for individuals with terminal diseases. However, at the turn of this decade the definition was changed to include individuals with “life-threatening” illnesses¹. This was to highlight the importance of considering palliative care much earlier in the illness trajectory so that individuals could benefit from receiving services earlier, rather than only in the terminal phase. It is recognized however that the term “life threatening” may be too broad. For the purposes of the regional program being proposed for Champlain, hospice palliative care is understood as being applicable for individuals with a progressive incurable illness.

The modern use of the term “hospice” originated in the 1960’s in the United Kingdom. In the early years, it focused on the terminal phase of life (referred to herein as “end-of-life care”), usually provided in free-standing facilities as well as home support programs. When the philosophy and approach was brought to Canada in the 1970’s, the term “hospice” could not be

¹For the purposes of this report, the term ‘individual’ will be used to describe those who are receiving or who would benefit from a palliative care approach. These same individuals may also be referred to, depending on the context, as clients, residents, members or participants.

used in French as it has a different, and often negative, connotation. The term “palliative care” (“soins palliatifs” in French) was therefore coined.

In Canada, the term “hospice” refers mainly to free-standing hospices focusing on end-of-life care as well as community-based support services for individuals and their families that these hospices provide. The conjoint use of the term ‘Hospice Palliative Care’ therefore allows us to cover the full spectrum of the illness trajectory, from early in the illness to the terminal phase and grief and bereavement as well as the many different settings where palliative care should be practiced.

WHY IS PALLIATIVE CARE NEEDED?

Clinical experience, supported by a considerable body of research, shows that individuals with progressive incurable illnesses experience a broad range of needs. The illnesses result in many physical symptoms and complications, along with different forms of psychological and spiritual distress and suffering. It also has impact on the social aspects of the individual’s and family’s lives, including work and the ability to support a family. Some individuals experience deep feelings of hopelessness, being a burden to others, and a loss of a sense of dignity. Others experience profound spiritual and religious crises when facing their deaths. Addressing all these needs fall within the range of care that is included under palliative care.

Most individuals experience several symptoms at the same time, depending on the stage of the disease. These include symptoms such as pain, shortness of breath, weakness and fatigue, anxiety, sadness, weight loss, loss of appetite and somnolence. About 35% to 50% of these symptoms are rated by individuals as being severe in intensity and significantly reducing their quality of life. Up to 80% of terminally ill individuals develop delirium, which presents as confusion and agitation. It is a very distressing complication for individuals and their families alike, particularly if the individual is experiencing hallucinations. Families may be haunted with images of their loved ones dying in confusion and agitation unless it is not treated promptly and effectively, and with sensitivity. Delirium is also often mistaken for uncontrolled pain and can result in the initiation of inappropriate treatment. About one-third to one-half of individuals

develop psychological problems with anxiety, sadness and feelings of hopelessness. About one third to half of these individuals go on to develop severe depression and/or anxiety.

Management of physical symptoms, although important, is only one of several components to providing palliative care. Early discussions about goals of care and advance directives are essential. Failure to do this results in inappropriate decision-making and inappropriate care being provided. Some studies, for example, have shown that up to one third of individuals with end-stage lung and heart diseases may inappropriately, end up in intensive palliative care units on artificial life support machines because these discussions were never held and the individual and their family were never provided the opportunity to prepare for end of life care. These inappropriate decisions result not only in a large burden of suffering for individuals and their families, but also high costs for the health care system as expensive, futile treatments are offered and emergency rooms are accessed to manage problems that were not anticipated or controlled earlier.

Decision-making includes decisions about whether to withhold or withdraw treatments such as artificial hydration (providing fluid by a drip) or artificial nutrition (providing nutrition via tubes), dialysis, ventilation support and whether or not to treat pneumonia or perform surgery. Numerous factors need to be considered when making these decisions. These include the benefits versus burden ratio of the treatments proposed, the individuals' and families' values and expectations, the feasibility of the treatments, the preferred setting of care (eg. a particular intervention may not be appropriate for an individual who prefers to be cared for at home rather than in a hospital), the estimated life expectancy, and the resources available. Ethical dilemmas may arise during the course of these discussions and need to be addressed. These may occur when individuals' and families' expectations are unrealistic or health professionals do not understand or lack sensitivity to individuals' and families' cultural and religious needs.

WHO SHOULD RECEIVE PALLIATIVE CARE?

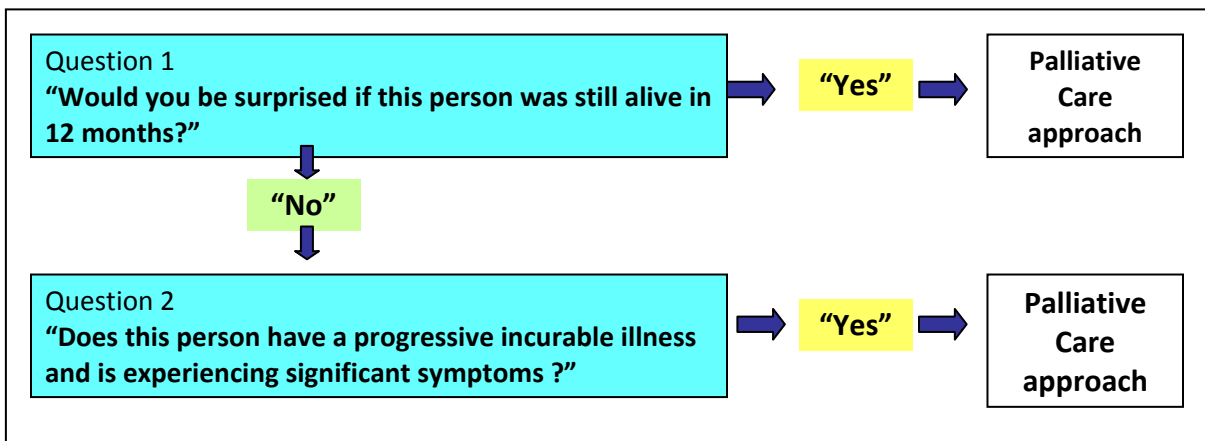
The question is often asked: "When is an individual palliative?" and "Who should receive palliative care services?" A more appropriate question would be "When would an individual and his/her family benefit from palliative care (also referred to as a 'palliative care approach')?"

Refocusing the original question allows us to initiate palliative care measures much earlier in the illness trajectory and not just in the terminal phase. It also integrates palliative care within other care approaches. For example, an individual may be receiving chemotherapy to control his disease while also having his symptoms managed. An individual with advanced diabetes mellitus and severe complications of the disease (renal impairment, nerve damage) receiving chronic care and chronic illness management may also benefit from the discussions about end of life care, advance directive choices and symptom management (e.g. nerve pain resulting from the diabetes) that a palliative care approach offers. The two care approaches, chronic care and palliative care, therefore become integrated to best meet the needs of the individual and his family.

Joanne Lynn (2000, 2004) developed a ‘no surprise’ question-based approach to identify when an individual would benefit from a HPC approach. As depicted in the table below, health professionals ask themselves the following question – “Would you be surprised if this person was still alive in the 12 months?” and if the answer is ‘yes’, a second question is then asked to determine if the person is experiencing significant symptoms. The decision to implement a palliative care approach is based on the response to these questions.

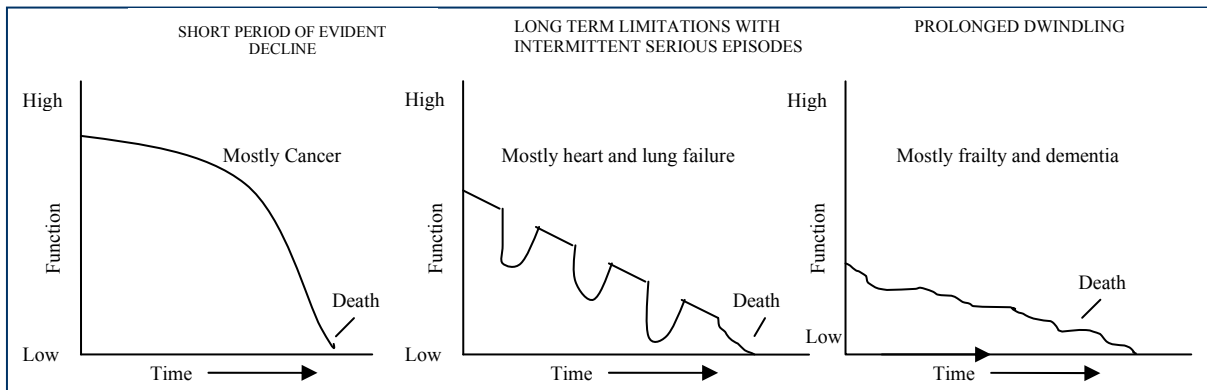
Lynn acknowledges that there is a significant degree of subjectivity to this tool and that some individuals identified this way may die quickly, while others may live a long time but would still benefit from a comprehensive service tailored to advanced illness and end of life. This clarification is particularly important in clinical settings where decisions around care delivery have a significant impact on the volume of clients and the administration of the service.

**IDENTIFYING THE PATIENT WHO WOULD BENEFIT FROM PALLIATIVE CARE:
CASE FINDING**



Lynn goes on to describe three trajectories that encompass the patterns that most people who live with chronic, progressive disease experience. As demonstrated in the figures below, the first describes a short period of obvious decline which is typical to cancer. The second demonstrates chronic illness with exacerbations and sudden dying. The third demonstrates the trajectory of individuals who are likely to die in later life with generalized frailty of all body systems or neurological failure such as Alzheimer’s and other dementia.

Illness Trajectories for Individuals Requiring Palliative Care:



WHO PROVIDES PALLIATIVE CARE? (Palliative Care Approach versus Specialist Palliative Care)

It is recognized that many different health professionals, volunteers and informal caregivers are involved in providing palliative care. The term “palliative care approach” has often been used to refer to good basic palliative care delivered by primary health care teams or specialists who are not palliative care specialists (e.g. oncologists, internists). The term is used to differentiate palliative care at that level from palliative care delivered by specialist palliative care clinicians or teams (“specialized palliative care”).

All service providers should have at least some basic competencies to initiate and maintain basic palliative care measures, including end of life discussions, advance directive discussions, pain and symptom management, supportive psychological counseling and care, and identifying social and spiritual needs of individuals.

Most of palliative care should be delivered at a primary health care level. A model that relies on the exclusive use of specialist palliative care teams to provide all the palliative care will not be able to meet the future needs of an ageing population and the anticipated increase in the number of people developing illnesses such as cancer and end-stage heart, lung and renal diseases. It is recognized however that primary health care and attending teams in hospitals require the support of specialist palliative care services, particularly for the management of the more complex and difficult cases.

There is, therefore, an important role for specialist palliative care teams, whether they are in hospitals or in urban or rural communities. In a *consulting* role, they provide advice and, sometimes, shared care service models (when the care is more complicated) to support primary health teams and other specialists caring for individuals with progressive incurable illnesses. In this capacity it is important that the specialist teams empower and enable the primary teams (and most responsible teams for individuals admitted to hospitals) to provide palliative care rather than taking over the care themselves as this develops dependency and does not nurture other primary care providers and specialist attending teams in their roles. Specialist palliative care services may take over the primary care role in a very small number of individuals with very complex needs.

Specialist palliative care services should also support secondary level palliative care services (eg. local palliative care physician or nurse champions in rural regions and smaller communities who have acquired more advanced training in palliative care but not full specialist-level training and serve as local resources in their communities). Two other very important roles for palliative care specialists is to develop and deliver education programs for their primary care colleagues and colleagues in other specialty areas as well as lead research in the field to improve the management of symptoms and service delivery.

WHERE IS PALLIATIVE CARE DELIVERED?

Palliative care, whether it is an approach provided by primary health care teams or by specialist palliative care teams, can be delivered in many different settings. In fact different settings and levels of care, as listed below, should be available to address the many different needs of

individuals and their families. The movement of individuals across these different settings as their needs change should be seamless and integrated.

Community based services including home care programs, community support services and primary health care clinicians and teams, with the support of specialist palliative care services (including pain and symptom management consultation teams) should be available for those individuals whose needs can be addressed at home and in the community.

Hospice beds should be available for end of life care for individuals who cannot be cared for at home because of their needs or who prefer to die in a hospice rather than home.

Palliative care units should be available to address the needs of individuals with very complex needs requiring a specialist palliative care service.

Hospitals, including cancer centres, acute care and complex continuing care, should have *palliative care specialist consult* teams to support the attending teams in caring for individuals.

Long term care homes should have staff trained in providing palliative care and should have regular access to palliative care consult teams.

Rehabilitation should also be available for individuals who still have many months of life left and could benefit from rehabilitation to keep them in the community for as long as possible.

PROFILES OF JOURNEYS WITHIN HOSPICE PALLIATIVE CARE

The following examples, taken from real life situations, describe individuals who have benefitted from receiving palliative care, what that care involved, and the different settings where the care was delivered.

CASE 1

A 72 year-old lady (Jane) has been diagnosed with advanced breast cancer which has spread to her lungs, liver and bones. Chemotherapy treatment has not been able to control her disease. Jane's wish is to be cared for at home for as long as possible. She is experiencing a moderate amount of pain and shortness of breath. She also has a large ulcer of her skin over her right breast as a result of the cancer which requires regular dressings. Her pain is over her right chest (at the site of the ulcer) as well as in her right hip. The pain worsens when she walks. She is taking Tylenol #2 for her pain. Jane's most responsible physician is her family physician who wishes to continue caring for her and is willing to do home visits. The physician also cares for individuals at the local hospice.

She is a widow and lives alone at home but has two daughter and 3 grandchildren who live in the city and are very supportive. Her two daughters work full time. Jane receives additional support through her neighbourhood community support agency who arranges for volunteers to drive her to her medical appointments, and matches her with a screened worker to help with home-making and home-maintenance.

Management

The Cancer Centre has activated, through the CCAC, palliative home care services. The nurse is visiting Jane twice a week for wound dressings and assessments. The family physician has activated a palliative care approach by initiating discussions with her about her goals of care and advance directives. She has requested a “Do Not Resuscitate” (DNR) Status which will allow a natural death without resuscitation attempts or being connected to artificial life support when she dies as this would unnecessarily prolong her life when its quality would be diminished. She has also been informed by her family physician that resuscitation in individuals with advanced disease such as this one is seldom successful.

The family physician starts regular treatment with morphine which begins to alleviate her pain and some of her shortness of breath and contacts the palliative care community specialist consult team for further advice. The team suggests that he do an x-ray of her hip and chest. These reveal cancer in her femur (a metastasis of her breast cancer), which is responsible for the pain there. The X-ray also shows fluid accumulation, also because of the cancer, around her right lung. This could be contributing to her shortness of breath. In discussions among Jane, her daughter, the family physician and the specialist palliative care team, a decision is made to refer her back to the cancer centre for palliative radiotherapy to her femur in the area of her hip as this is very effective palliative treatment for pain. She is also referred to the Shortness of Breath clinic at the Cancer Centre where the team places a small tube in her chest to drain the fluid as a palliative intervention. The tube is left in and can be drained at home whenever the fluid builds up, thereby avoiding visits to the Emergency Room. These measures prove to be very useful and makes the individual much more comfortable.

The physician and home care team then also discuss with Jane and her family, as part of the palliative care approach, where she wishes to be taken care of and what other supports might be needed. She wishes to be at home. The family physician and CCAC commit to try making this happen as much as possible, but also inform her and the family that if her needs become very high and cannot be addressed in the home setting, she may need to explore placement to a hospice. They suggest day hospice care services provided by the local hospice service. The family is relieved by this as they were feeling guilty that, because of their other work and family responsibilities, they may not be able to care for her at home until she dies. Jane is also relieved by this as she feels a burden to her family. The decision is therefore made that the priority will be to attempt to keep her at home for as long as possible and even to the end of possible, but that if it becomes too difficult and burdensome on Jane and her family and the available resources, consideration would be given to moving her to a hospice.

Jane and her family also admit that they are struggling to come to terms with the Jane’s illness at an emotional level. They are finding it difficult to talk to on another about the losses that they are currently feeling and those that they anticipate in the future. In

addition, Jane's daughters are feeling stretched to support their mother and continue to manage full time work and care for their own families. Information regarding caregiver support programs and bereavement support programs is provided to Jane and her family and they are supported to connect with these programs.

CASE 2

A 62-year-old man (John) is diagnosed with amyotrophic lateral sclerosis (ALS). His neurologist breaks the news to him and explains to him the disease. He informs him that it appears as though he has an aggressive form of the disease that appears to be progressing rapidly and that his life expectancy is probably in the order of 12-18 months. The neurologist begins to discuss with him care options, in particular the need for a palliative care approach. John and his wife are distraught with this news and frightened by the idea of "palliative care". The neurologist explains to him that this would focus on controlling symptoms that he may experience, including shortness of breath and pain, but decides not to proceed further because of the John's distress. An appointment is made by the neurologist for John to return a week later for further discussions and supportive counseling. He is referred back to his family physician.

Management

A few months later, John begins to experience more weakness and starts to use a wheelchair to get around. He is also beginning to experience pain in his legs and shortness of breath. His family has noted that on occasion, he is beginning to choke on his food. He visits his family physician, who is unsure how to proceed in controlling his symptoms as he does not have much experience with ALS. The family physician contacts the palliative care specialist consult team and requests that John's care be transferred. The consult service encourages the family physician to remain involved and offers to provide support in caring for John. The CCAC case manager also commits to supporting the family physician. The family physician, after some initial reluctance, agrees with the arrangement.

The consult team recommends that the family physician start morphine treatment at a low dose to help the shortness of breath and pain. The family physician is initially concerned that this may stop John's breathing. The consult team provides the family physician with the research evidence to show that this treatment is safe and very effective. The treatment is started with excellent effect. John feels much more comfortable. The team also makes suggestions for management of increased drooling that the individual is experiencing because of the disease. Importantly, the team initiates a discussion about goals of care and advanced directives. They inform the family physician about these discussions.

The discussion on goals of care allows the team to address the issues of resuscitation and avoidance of a ventilator (being hooked up to a machine) when his breathing becomes more difficult in the future. The team also discusses issues around nutrition given that he is now having difficulties swallowing. Ethical issues regarding withholding artificial nutrition are discussed. Although the family is in agreement with the palliative team's suggestion that hooking him onto a ventilator would not be appropriate and would simply prolong suffering, they have great difficulties in withholding artificial nutrition.

They recognize that he is no longer able to take food by mouth and will require tube feeding. After an ethics focused discussion between the Palliative Care Consultation Service, John and his family as well as the family physician and neurologist, a decision is made that under the circumstances, they would proceed with artificial feeding using a feeding tube. However, John and family agree that should the tube begin to become a major burden, including causing aspiration pneumonia, they would stop the feedings.

The Palliative Care service is also able to advise on initiating a non-invasive ventilation support using a treatment called BiPaP. This is a relatively small device, which consists of a special mask and a small machine, can be brought into the home to help him breathe during the night when his oxygen levels tend to become low and he develops shortness of breath, confusion and headaches. It is a palliative intervention that is much better than putting him on a ventilator. Throughout all this process the family physician continues to see John and is in close communication with the CCAC nurse and palliative care consult team.

John dies at home several months later surrounded by his family. His family physician is also present. The family physician feels that this has been a very rewarding experience and feels that he is interested in taking on more palliative care patients in the future.

CASE 3

An 86 year-old lady (Betty) with advanced dementia has been a resident in a long term care home for several years. Her condition is now deteriorating. Over the course of the last year she has been admitted to hospital twice for treatment of aspiration pneumonia and kidney function impairment. She has also received several treatments with antibiotics for lung infections while in the facility. She is now having difficulties swallowing and is increasingly bed-bound. Given the progression of Betty's dementia and the other complications she is experiencing, a decision is made to activate a palliative care approach. The caregivers at the residence are also concerned that she is having a lot of pain and they are not sure what to do to control it. They are wondering about morphine treatment. The palliative care specialist consult nurse is called in to help the team with decisions regarding Betty's care.

Management

The nurse assesses Betty and determines that her groaning and facial expression changes are related to delirium (confusion) rather than pain and that pain medications would not be appropriate. Management of her delirium would be more appropriate. A family conference is arranged to discuss the goals of care. Her daughter, who is the designated decision-maker for her mother, attends with her two other siblings. Team members discuss the pros and cons of further antibiotic treatments and transfers to hospital if she develops an infection again. A decision is made to focus on comfort care rather than transferring her again to hospital for aggressive treatments. Discussions are also held regarding her nutritional needs. These turn out to be challenging. The family is very concerned that she will starve to death if she is unable to eat on her own. They want to initiate tube feeding. The palliative care team explains that because of her overall deteriorating condition that she be allowed to die naturally from her disease without prolonging her life with artificial feeding. The family refuses this approach as it is against their religious beliefs. A compromise is made to initiate

feeding through a nasogastric tube but that if there is evidence of her condition deteriorating despite the feeding or evidence that the feeding tube is making her uncomfortable that the treatment will be stopped. The family accepts this approach.

CASE 4

A 13-year old child (Billy) was diagnosed with an incurable kidney cancer 2 years previously. Despite surgery and chemotherapy, his cancer has progressed. He lives in a small community 40km away from the children's hospital in the city and is cared for in the community by his family physician. His family physician however has been receiving a lot of advice and support from the pediatric team at the Children's hospital. Billy is experiencing abdominal pain, nausea and increasing fatigue and weight loss. His family is distraught. The family physician has already initiated a palliative care approach by providing supportive counsel to Billy's parents and 10 year old sister and has also connected the family with a hospice day support service for family members. The family physician is however not sure on how to proceed with managing Billy's symptoms as this is not something that she has to deal with often. She contacts the pediatric palliative care service at the Children's hospital for assistance.

Management

Billy is seen at the Children's hospital by the pediatric palliative care team who initiate pain treatment using a pump. The pediatric palliative care service also provide counseling for the child, who knows that he is dying but has some last wishes, and the family. They discuss care plans and how to manage any emergency that may occur. They contact the FP physician and discuss the plans with the family physician and a decision is made to proceed with a shared care model in which the pediatric specialist palliative care team will work closely with the family physician and CCAC nurses to provide care for the individual. In the following weeks there is regular weekly communication between the specialist palliative care team and the family physician and nurse. The medications are adjusted and the family physician meets the family regularly. The palliative care specialist team have also paid a visit to the individual's home with the family physician and nurse. Because of increasing symptoms and distress of the family, the individual is admitted for a week to the pediatric hospice. Billy's mom is able to stay with him during the stay in hospital. A week later, with the pain and nausea under much better control and parents that are more rested, he returns home again. The hope is that he is able to stay at home until he dies. However, contingency plans are made to admit him to the local hospital for end of life care (as this is closer to all his family and his friends) if dying at home is not possible.

CASE 5

A 56-year-old man (Dave) is admitted to an acute care community hospital after presenting with a two-month history of abdominal pains. He has developed jaundice. Tests while in hospital show that he has a large tumor in the pancreas which is blocking his bile duct. Scans also show that there are small tumors in the liver. This is consistent with metastatic pancreatic cancer and a biopsy confirms this. Dave and his family are very anxious and fearful about what is happening. He is experiencing severe abdominal pain as well as nausea and severe weight and appetite loss. He is concerned that he will starve to death if he does not eat more and gain weight.

Management

The Internal Medicine team in the hospital that has admitted him activates a Palliative Care approach. This includes breaking the news to him and his family that his disease is progressive and that his life expectancy is in the order of several months and providing psychological support to help them with this bad news. They discuss with him treatment options, which include palliation of his symptoms and palliative chemotherapy with the goal of reducing pain. They also introduce the concepts of advanced directives and resuscitation status but tell him that these discussions can be returned to in more detail once he and his family have dealt with the news. The internal medicine team also starts him on a regular opioid treatment to manage his pain. They consult the palliative care consult specialist service in the hospital for advice on managing his weight loss as well as other recommendations to improve his quality of life. The Palliative Care Consult team assesses Dave and his family and determine that the pain is well controlled with the measures that the attending team have initiated. The consult team also determines that he is not in a major depression but has a sad mood as a result of this diagnosis. The palliative care consult team suggests working with the attending team in providing supportive counseling. Pharmacological treatment for his sadness is not required at this time. However, if his sad mood worsens a consultation to the psychology team should be considered. The consult team explains to Dave and his family that the weight loss is a complication of the cancer and that unfortunately it cannot be reversed when the disease is very advanced, even with increased eating or artificial feeding. However, medication would be available to try and help his appetite as a quality of life measure.

The team's social worker explore the social needs of this family and discover that there are significant financial concerns as his wife has no work and he has a disabled son living at home with him. As part of the palliative care approach, the team also initiates discussions about who will care for him at home, including Homecare nursing services and explore the availability of his family physician to care for him in the community and do home visits. With respect to his pain control, the consult team informs him that if pain were to worsen despite his current treatment, there are other measures that can be taken to improve pain control. This includes referring him to the complex pain clinic at the local university hospital where an anesthetist can perform a special anesthetic block of the nerves near his pancreas (celiac plexus block). Dave and his family are also connected with the Community Care Access Centre (CCAC) Palliative Care case managers. During the discussions, he has said that he feels that there is no hope for him. The team has been able to refocus his hope in a way that is more realistic. Dave, because of the assistance of the consult team and other resources, working with the attending team, is able to be discharged sooner from hospital.

CASE 6

A 68-year-old woman (Joan) has metastatic colon cancer. Unfortunately the cancer has spread despite surgery and several cycles of chemotherapy treatments. She has been cared for at home and has Palliative Home Care services in place and a family physician that does home visits and is following her closely. Her husband is a 76-year-old man who is frail. They have three children who live in the city and are very supportive and visit often. All three children hold their own jobs and have their own families. Joan is now very weak and mainly bed-bound. She begins to experience episodes of intestinal obstruction where the cancer is blocking the intestines. This is resulting in bouts of severe pain and nausea and vomiting. Her care needs are now such that it has become difficult for her to remain at home despite the home care services, family physician involvement and the support of a palliative care consult service. A decision is made to transfer Joan to a hospice.

Management

In the hospice, as part of a palliative care approach, her family physician, working closely with a very experienced palliative care nurse consultant, they adjust her pain medications and give it by injection as she cannot swallow. They start treatment with a medication called octreotide to control her bowel obstruction and give her some fluid by a subcutaneous needle. They also start an anti-nausea medication. This is very helpful in making her comfortable. The hospice team also identifies that the husband is very distraught to see his wife dying and initiate bereavement care for him and the family.

Three weeks later her condition begins to change and there are signs that she is in the terminal phase of her life with just days to live. She drifts in and out of consciousness, but is comfortable. The family is informed of this and a decision is made to withdraw the artificial fluid through the drip as this is no longer contributing to improving her quality of life. Some of the family members however are concerned that withdrawing the fluid is euthanasia. An ethics-based family meeting is held with the family physician (who is accompanied by a family medicine resident who is training in palliative care), nursing team, a palliative care specialist consultant and the family to discuss this. The team reassures the family that providing hydration is now futile and will not contribute positively to Joan's quality of life but is now a burden as it is causing fluid to build up in her lungs. They explain that this is not euthanasia. The family members are reassured and the drip is discontinued. Joan dies comfortably several days later surrounded by the family.

CASE 7

A 76-year man (Ed) with severe heart failure is being cared for his family physician in the community. Ed receives additional support through his neighbourhood community support agency who arranges for volunteers to drive him to his medical appointments, and arranges for delivery of hot low sodium meals three times a week. In addition, when he is feeling well enough, Ed attends a weekly Diners Club program where he enjoys social contact with other seniors.

He has had several admissions to the heart hospital to manage his heart failure and related complications, including abnormal heart rhythms. He has a pacemaker to control the heart rhythm. It has a defibrillating function that will provide electric shocks directly to the heart if

it were to stop. Ed has now also developed severe kidney impairment. It would be important to initiate a palliative care approach at this time if it has not already occurred.

Management

The palliative care approach would include discussions by his family physician and the team at the Heart Centre about goals of care, advance directives, symptom management (in this case it includes chest pain, shortness of breath, nausea, and depression), whether or not to proceed with renal dialysis and what to do about the pacemaker. A palliative care specialist team could be called in to assist with these discussions and to make recommendations.

1. INTRODUCTION

The health care system in Ontario is currently experiencing some major challenges that are having a significant impact on the ability of our system to provide the level of service residents expect and deserve. These include both economic and health human resource issues that have resulted in the overcrowding of emergency rooms, inappropriate utilization of acute care hospital beds and long waiting lists for long-term care.

The Champlain LHIN recognizes that the development of a regional approach to service delivery can make a significant contribution to addressing these challenges and as such, has focused on sectors of the system that have the potential to make the biggest impact, including hospice palliative care (HPC). To move this agenda forward, the LHIN gave the Champlain Hospice Palliative and End of Life Care Network the mandate to develop a comprehensive and integrated palliative care service delivery plan for the region.

The plan put forward in this document describes the development of a Regional HPC Program for Champlain. The key components and related recommendations are based on the results of a major planning effort involving individuals across the region with an interest in improving HPC service delivery.

The benefits of a regional approach to service delivery include an enhanced coordination of care, the seamless transition for individuals between services and the reduction in confusion for individuals, their families and health providers with respect to which service to access and where and how to access it. Ultimately, the goal of the Regional HPC Program is to ensure

"There have been previous plans and documents. I hope that this time the stakeholders can get this moving and MAKE IT HAPPEN."
SurveyMonkey Respondent

individuals requiring HPC have access to a coordinated, accessible and accountable palliative care service delivery system in the Champlain region, thereby, contributing to the three overall aims of the Champlain LHIN's Integrated Service Plan (2010-2013):

- Improve the health of Champlain residents
- Improve their experience with the health system, and

- Improve the performance of an accountable and sustainable system

Effort has been made to also ensure a planning process that is consistent with provincial efforts to standardize HPC services.

2. CURRENT HOSPICE PALLIATIVE CARE SERVICES IN CHAMPLAIN

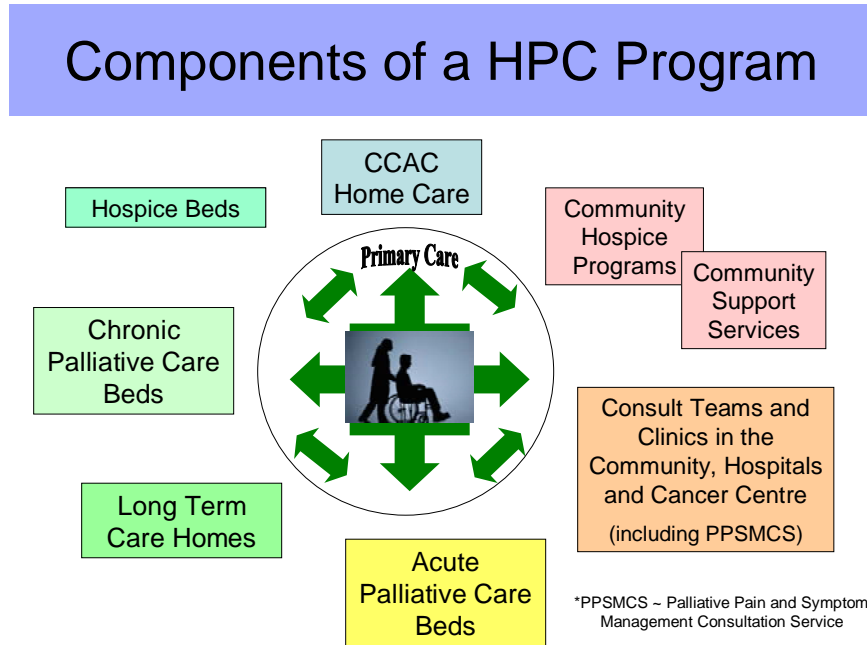
The provision of palliative care requires a wide range of services and professionals to address the physical, psychological, spiritual and social needs of individuals and their families. It also requires access to rehabilitation resources for those individuals whose life expectancy is still in the order of many months and even years to optimize their functional levels and mobility for as long as possible. Access to complementary and recreational therapies as well as bereavement support are essential components of a service that provides the full scope of resources required. Close collaboration between the various professionals and disciplines with their respective skill sets is essential. The importance of education of health professionals, volunteers and informal caregivers should not be underestimated as this enhances quality of care, sustainability and broader outreach.

To meet the broad and ever-changing needs of individuals requiring HPC as their illnesses progress, HPC services are required across a variety of settings including home care and a strong primary health care basis, both in urban and rural settings, to support individuals at home. This also includes hospice day programs to support individuals and their families. Mobile palliative care specialist consult teams are needed in the community and in acute care hospitals to support the attending professionals and teams. In rural regions individuals and teams with additional training in palliative care (not at a specialist level but more advanced than at a primary care level) can serve as champions and supports for their local colleagues.

Sufficient acute palliative care beds in designated palliative care units are required to care for those individuals with very complex problems that require intensive interventions by specialist palliative care teams. A sufficient number of hospice beds are essential for those individuals who, for a variety of reasons, cannot be cared for at home but who do not require the acute care levels of acute medical and palliative care units. It is recognized that some individuals may

require admission to hospice palliative care beds because their needs cannot be met at home but their life expectancy is longer than that usually associated with hospice stays.

The following diagram summarizes some of the key settings and services required in a coordinated HPC regional program.



Although some significant gaps in HPC services exist in the Champlain region, the region has several important services and resources on which to build a strong regional program. Some of these programs are highlighted below.

Primary Level Palliative Care

There is a need to increase the number of family physicians and primary health teams actively involved in providing palliative care to increase the long term sustainability and access to HPC. This would add to a strong but still relatively small cohort of family physicians and primary health care teams providing palliative care.

In the Ottawa region some of the primary palliative care in the community is being delivered by a small group of family physicians (FPs) who provide palliative care: The Community Palliative Care Network (a physician-only group of 5 independent family physicians with a special interest

in palliative care) and Palliative Care Outreach Program (an inter-disciplinary HPC team providing primary care services mainly in the west end of the City of Ottawa).

In rural regions, palliative care is provided by family physicians. In some areas there are family physicians with a special interest in palliative care and in some cases additional training. These physicians can form the nucleus of a stronger secondary level of support for their local colleagues with consultation support, when needed, from the Bruyère Palliative Pain and Symptom Management Consultation Service (PPSMCS).

Several challenges remain to increasing family physician involvement in providing palliative care. Two of the main ones are a shortage of family physicians in the region and busy workloads. Some family physicians are concerned that their level of expertise in the area is insufficient. This can be addressed through education and close support by consult teams. The new billing codes of the Ontario Ministry of Health and Long Term Care (MOHLTC) for providing palliative care by family physicians have addressed previous concerns of inadequate remuneration for family physicians for this type of care.

Home Care

The Champlain Community Care Access Centre (CCAC) provides palliative care in the home and community to approximately 2600 individuals annually. Case manager's work with the individual and their family to develop and co-ordinate individual care plans to meet the individual's need through CCAC provided services or through linking the individual/family with other community resources available to this client population. CCAC contracted services include nursing, occupational therapy, physiotherapy, dietetics, social worker, personal support worker as well as equipment and supplies. Case managers reassess care plans on a regular basis to meet the changing needs of the client.

Community Hospice Programs

Residents in both rural and urban areas of Champlain benefit from access to a number of volunteer-based programs that provide palliative care support to individuals in their homes or in a day hospice setting. The Hospice at May Court, Friends of Hospice in Ottawa, Hospice Renfrew, Cornwall Hospice, Dundas County Hospice and the Beth Donovan Hospice (located in Kemptville) provide important community-based services, including day hospice programs and

individual and family support resources. Most of these operate without significant levels of funding and provide a range of services to individuals and their families including in-home volunteer visiting/respice, day hospice programs, bereavement and caregiver support, family and support groups and assistance with transportation.²

The Palliative Pain and Symptom Management Consultation Service (PPSMCS):

The PPSMCS is a bilingual program funded by the MOHLTC, hosted and supported by Bruyère Continuing Care. It is a consultation service, made up of an inter-professional team of palliative care specialist nurses and physicians, which supports health care professionals and builds primary care team capacity by providing access to palliative care expertise through consultation, advanced palliative care education, coaching and mentoring. The team works collaboratively with family physicians, CCAC, nursing agencies, long-term care homes, residential homes, hospices, and community hospitals. In the area of education it collaborates with colleges and universities and other palliative care resources across Champlain. This team has over the years worked closely with rural teams in areas such as Renfrew and Hawkesbury to build up their palliative care capacity. It has consultation nurses in the Renfrew/Pembroke region and a position vacant for the eastern counties region. These nurses provide a consultation service in these local regions and serve as a link with the tertiary specialist services out of Bruyère. The PPSMCS has also in recent months successfully been providing physician consult service at the Queensway Carleton community hospital in western Ottawa and the Mission Hospice.

The PPSMCS service is hosted and supported by Bruyère Continuing Care and offers 24/7 consultation advice to all health professionals. The team does not take on the primary care role of individuals but works with the individual's primary physician and team.

Hospital-Based Specialist Consultation Teams (includes Cancer Centres)

The Ottawa Hospital is the largest acute care hospital in the Champlain area with a total of 1,066 beds (located on the General and Civic Campuses). HPC for inpatients is delivered using a consultation model with a dedicated inter-professional palliative care team. TOH also provides palliative care clinics for outpatients of the Cancer Centre (3 half day physician/nurse clinics and

² A small number of organizations receive funding from the MOHLTC including: Beth Donovan Hospice, Dundas Hospice, Hospice at Maycourt, and Friends of Hospice Ottawa.

1.5 full-day nursing clinics). There is also access to the Complex Pain Clinic, a collaboration between Palliative Care and Anaesthesia at the TOH for access to interventional procedures such as regional blocks and epidurals for pain control.

The Queensway Carleton Hospital provides a consultation service that consists of an advanced practice nurse (APN) and a nurse specialist. Physician consultation is provided either by telephone or in person by PPSMCS on request of the APN and nurse specialist.

The Montfort Hospital does not, at present, have a palliative care model in place. However, a physician is currently undergoing palliative care fellowship training with the goal of leading the establishment of a consult team at the hospital.

At the Children's Hospital of Eastern Ontario (CHEO), a pediatric palliative care team works closely with other CHEO services and community partners, including Rogers House, the pediatric hospice, located on the hospital grounds.

As previously mentioned, there is a need to conduct a more detailed environmental scan to appropriately capture HPC initiatives and services available across Champlain. This would include connecting with community hospitals across the region including hospitals in Renfrew County (Arnprior and District Memorial Hospital, Renfrew Victoria Hospital, St. Francis Memorial Hospital in Barry's Bay, Pembroke Regional Hospital and Deep River and District Hospital), hospitals in Eastern Counties (Hawkesbury and District Hospital, Glengarry Memorial Hospital, Winchester District Memorial Hospital and Cornwall Community Hospital and St. Joseph's Continuing Care Centre) and hospitals in the area of North Lanark/North Grenville that fall within the Champlain LHIN region (Almonte General Hospital, Kemptville District Hospital and Carleton Place District and Memorial Hospital). While a number of these hospitals have HPC services in place, it is important to ensure the capacity to provide palliative care consultation support and to broaden access to all.

HPC Bed Services

In an integrated system, a range of HPC beds should be considered to ensure the system provides a balance of services to meet the needs. The working group looking at the issue of beds

has come forward with definitions and associated standards for Intensive HPC Beds, Acute HPC Beds, Chronic HPC Beds and Residential Hospice Beds. Current HPC availability is as follows:

Residential Hospice Beds

There are four residential free-standing hospices in the Champlain region with a total of 25 adult hospice beds and 8 pediatric hospice beds (Rogers House). The Hospice at May Court provides 9 beds. These, apart from the beds available at the Mission Hospice (see below), are the only hospice beds in the Ottawa area. The shortage of sufficient hospice beds in the Ottawa area and the absence of HPC beds in eastern and western Ottawa represents one of the largest gaps in HPC services in the region, resulting in many individuals who are unable to return home because of their needs remaining in acute care facilities.

The other adult hospice beds are in Hospice Renfrew (6 beds) and Cornwall Hospice (10 beds). There are between 8 to 15 (varies according to needs) HPC beds at the Ottawa Mission for terminally ill individuals who are homeless. These services are not part of the MOHLTC funding formula, but are funded through, and supported by, Ottawa Inner City Health. The PPSMCS provides a consultation service to the Mission Hospice as well as an education program.

Planning for residential hospices is also taking place by local groups in Kemptville, Ottawa West and Hawkesbury.

Funding levels for residential hospice beds were set in 2005 by the Ministry of Health and Long Term Care as part of the End of Life Strategy. Funding flows through the Champlain CCAC, and accountability agreements between the CCAC and the respective organizations are in place. The difference in Ministry funding, which accounts for only about 40% of the hospices operational costs is made up through fundraising efforts of the organizations involved. This is proving to be very challenging and questions are arising as to the sustainability of the “stand alone”, independent health facility residential hospice model.

The Hospice Association of Ontario (HAO, 2010) has estimated the cost of a ten bed residential hospice at approximately \$1.6M annually, or about \$430 per day. Champlain Residential Hospices are providing care for a considerable lower rate of \$300 to \$400 per day, with the LHIN

providing about \$160 to \$200 of that under the current funding formula. Because of the cost differential between residential hospice beds and hospital beds, there is opportunity to reduce overall costs by moving beds out of hospitals and into other settings.

The lack of hospice beds and the challenges with respect to the sustainability of existing beds is an important issue that needs to be addressed as one of the first activities of the Regional Program.

Bruyère Continuing Care Acute Palliative Care Inpatient Unit

The Acute Palliative Care Unit, located at the Élisabeth Bruyère Hospital, is a 36-bed bilingual unit that admits individuals with complex problems as well as individuals with end-of-life care needs. It is the largest academic palliative care unit in the country and has contributed considerably to the training of health professionals in the region. At any one time, one-third to one-half of individuals has high medical and nursing requirements while a half to two-thirds has moderate intensity needs. Some may be admitted for a short period of time to manage difficult pain and symptoms, as well as complex psychosocial and spiritual needs. Other individuals with a mixture of high and moderate intensity care needs may be admitted for care at the end of life when their care needs cannot be met in other settings. As an academic palliative care program, the palliative care team mentors learners from various disciplines, professions and settings.

Need for Additional Beds

There is no generally accepted, standard method for projecting HPC bed needs. Several high level estimating methods are often cited (e.g. Erie St. Clair Palliative Care Report 2008) and are used in the table below.³ In 2006, Bruyère commissioned a review of its palliative care program to help define the bed requirements for Ottawa and did identify a need for additional HPC beds. However, the study only offered a breakdown of bed type requirements for “acute” and “non-acute” beds with no reference to location within Ottawa.

Results of the analysis clearly indicate the need for additional beds in both the east and west Ottawa areas. Rural areas taken as a whole indicate there may be some gaps in service, but this

³ This is a preliminary review of bed requirements. The need for a more detailed analysis and formal bed plan has been identified in the document.

is difficult to clearly define as the projections did not define needs across the LHIN and did not take distances into account.

Projected Need for Beds							
Champlain Communities of Care	Renfrew County	North Lanark North Grenville	Ottawa West	Ottawa Centre	Ottawa East	Eastern Counties	Champlain.
Population 2006	97,545	46,952	368,998	229,674	212,325	190,583	1,147,209
Bruyere Review^{II}							96 to128
Beds - Australia*	6.5	3.1	24.7	15.4	14.2	12.8	76.7
Beds – Fraser Health**	7.5	3.6	28.3	17.6	16.3	14.6	87.9
Average of Methods	7.0	3.4	26.5	16.5	15.2	13.7	82.3
Current Inventory***	6.0	0.0	0.0	41.0	0.0	10.0	57.0
Difference	1.0	3.4	26.5	-24.5	15.2	3.7	25.3

*Australia - Ratio is 6.7 specialist palliative care inpatient beds per 100,000 population

**Fraser Health - 7.66 beds per 100,000, 26% for tertiary care

***Includes 36 Bruyere Beds

^{II} The review estimated that the Ottawa area alone requires about 66 to 88 hospice beds, and approximately 20 acute beds.

Numbers do not include 15 hospice beds at The Mission, due to specialized patient population

Long Term Care

The Champlain region has 60 LTC facilities representing 7,388 beds. The majority of LTC facilities integrate palliative care for residents as part of the resident’s continuum of care. However, there continue to be gaps in the palliative care provided in many of the facilities. Many LTC homes access CCAC palliative care services for support with certain palliative interventions (i.e. analgesic continuous infusion pumps and intravenous therapy). The CCAC role is of a supportive nature typically in terms of teaching the LTC home staff to do the treatment, or infusion pump, and then discharging once the teaching has been done. Primary care physicians caring for

individuals in these facilities and staff have access to the PPSMCS team and have had the opportunity over the years to receive components of palliative care education through MOHLTC Initiative 1.

Location	Facilities	Total Beds
Eastern Counties	18	1592
Ottawa	28	4700
N. Lanark/ N. Grenville	4	308
Renfrew County	10	798
Total	60	7398

Source: Champlain LHIN Environmental Scan, 2006

Residential Care Facilities

It is important to differentiate between Long Term Care and Residential Care Facilities (commonly known as retirement homes). Long Term Care facilities are regulated by the Ministry of Health and Long-Term Care. Residential care facilities currently come under the Landlords and Tenant Act and are not regulated by the Ministry of Health and Long-Term Care.

There are over 100 retirement residences listed on Champlain CCAC healthline web-site. Similar to LTCH, many older persons living in residential care suffer from chronic diseases and will likely require palliative services at some point. Medical care is provided by primary health care physicians. It is important to note that the ability to provide palliative care in retirement homes varies considerably. While some level of personal support services is generally available, there may be limited registered nursing staff. The Champlain CCAC augments services in residential care settings as per their typical basket of service, but does not replace the supports that the client already has in place or is entitled to through their contract with the residential care facility.

Other HPC Resources

Palliative Care Rehabilitation Service

A new outpatient palliative care rehabilitation program (twice weekly) opened in February 2010 at Bruyère Continuing Care at the Elisabeth Bruyere Hospital. The program, focusing on functional and nutritional status, provides an 8 week rehabilitation program to individuals who still have a life expectancy of many months and even years. The goal, using a rehabilitative approach, is to assist individuals to remain mobile and functional longer in the community . The service is provided by an inter-professional team consisting of a physician (oncologist/palliative care specialist), nurse, nutritionist, physiotherapist, occupational therapist and social worker. Individuals have access to the gym services and expertise of Bruyère Continuing Care.

Complex Continuing Care (CCC)

Champlain has two CCC facilities (Bruyère Continuing Care in Ottawa and St. Joseph's Continuing Care Centre in Cornwall). Individuals with complex needs, such as individuals requiring ventilator, complex wound care and support with neuromuscular diseases, are cared for in CCC. There are also several CCC units in hospitals across Champlain.

Division of Palliative Care, University of Ottawa

The Division of Palliative Care, University of Ottawa currently has 13 specialist palliative care physicians (total of 11FTE), all with advanced training, fellowships and residencies in palliative care. The physicians provide specialist coverage at The Ottawa Hospital, Bruyère Continuing Care and the Palliative Pain and Symptom Management Consultation Service (PPSMCS). The Division is division under the Department of Medicine,. University of Ottawa. It has an academic mandate that includes clinical research, education research, and education.

Other Services in the Community

There are a range of services offered in the community that, while they are not specific to hospice-palliative care clients, support individuals who meet the definition of those who benefit from a HPC approach.

I could have used child care, cooking help, housework help, etc. but there was no funding for that.
Hospice Day Program Client

These services include: Care for the Caregiver, Bereavement Support, Community Support Programs and many others funded through many different avenues.

Hospice Palliative Care Program Data

Service Provision

Attempts have been made to collect information on program statistics related to the delivery of HPC. Unfortunately, it is very difficult to collate data or make any comparisons between services due to the lack of common metrics, dissimilar definitions of indicators and absence of any reporting framework for HPC services. The need to address this challenge has been identified as a priority recommendation later as part of the Regional HPC Program.

A brief summary of program statistics for organizations can be found in Appendix A.⁴ These highlights attempt to demonstrate the current level of service delivery among a selection of organizations that have established palliative care teams and provide a significant proportion of service to individuals with progressive, incurable illness.

In November 2009, the Champlain CCAC reduced the number of services hours available to clients in an effort to address the organization's budget deficit. This cutback, which lasted for approximately 3 weeks, had a significant impact and ripple effect on many aspects of the health care system. For example, during that time frame, The Ottawa Hospital's mean number of days waiting for a hospice or palliative care bed increased from an annual average of 5.4 days in 2009 to 11.1 days. In addition, their number of days on the palliative care service increased from an average of 9.1 days in 2009 to 27.0 days.

Financial Resources for HPC

An effort has also been made to provide an overall estimate of current funds in the health care system that are dedicated to providing HPC. Budget estimates for direct costs have been received from The Ottawa Hospital, Bruyere Continuing Care, Queensway-Carleton Hospital,

⁴ This list of programs in Appendix F does not include all organizations with HPC programs. A more detailed scan is required.

CCAC, Rogers House, Hospice at May Court, Hospice Renfrew and Cornwall Hospice total approximately 22 million. It is important to note that this figure:

- Does not include the 60-80% fundraising portion of the residential hospice budget (which is a requirement to support operations)
- Does not include funds from other organizations in Champlain that provide hospice palliative care (a more detailed environmental scan is required)
- Includes supplies and equipment in organizations with dedicated beds and the CCAC, but not for organizations with a consultation team only.

Physician Billing for HPC Services

Changes to physician billing codes over the past few years have addressed some of the compensatory challenges with respect to providing HPC and now recognize the increased amount of time required for counseling and coordinating care. As demonstrated in the table below, there were 217 unique physician billing palliative care. 137 physicians billed palliative care ten times or less. The majority of billing is done by a small number of physicians. These include community palliative care physicians as well as palliative care specialist teams at The Ottawa Hospital and Bruyère Continuing Care. The statistics also reveal that there is a significant number of physicians providing palliative care as a small part of their practice.

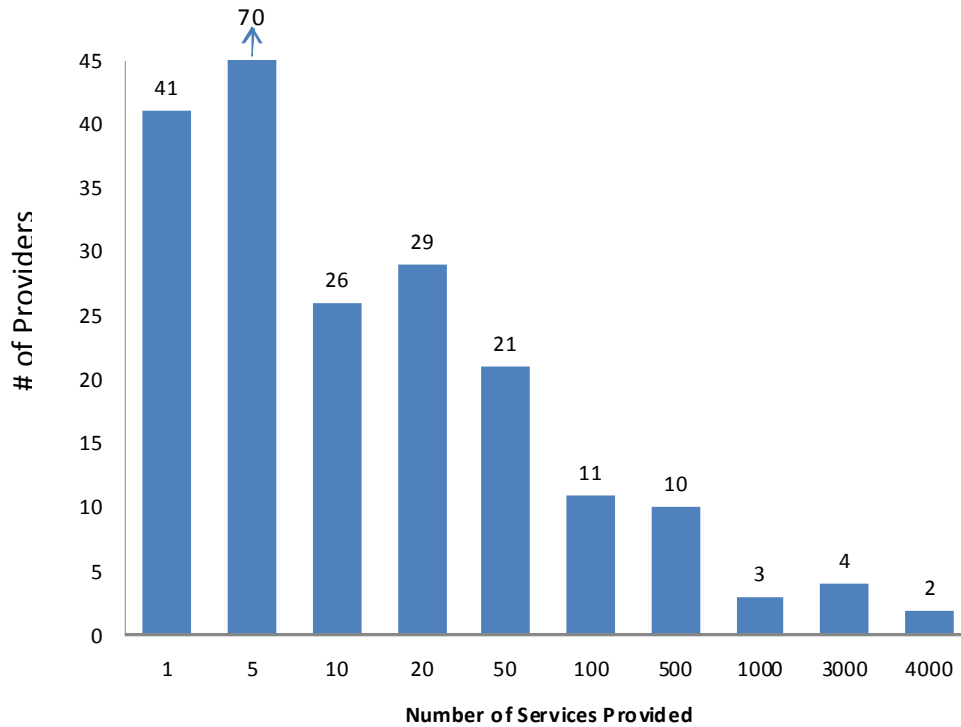


Figure 1. Frequency distribution of number the providers and palliative services billed.

3. PLANNING PROCESS

As a first step in the planning process, a retreat was held in April 2009 with approximately 70 participants representing a wide ranging of service delivery sectors, geographical areas and disciplines involved in palliative care delivery in Champlain. The purpose of the Retreat was to review the current service delivery system, explore the need for restructuring and examine priorities that need to be addressed in order to move toward integration. The Network used the outcomes of the retreat to develop a business plan which described the current state of HPC in Champlain, the argument for regional systems planning and an outline for the proposed next phase of planning related to the model development process.

Building on the outcomes of the Hospice Palliative Care Retreat, working groups, with representation from across the Champlain LHIN, were then established to review the current state of service delivery, explore best practice models and make recommendations for service improvements in each of the following areas: services in the community, bed allocation, HPC in

rural settings, HPC in long-term care homes, e-health, HPC consultation services, and patient flow mapping/service accessibility. A focus group format was used to engage primary care providers in discussions of HPC given the critical role they have in supporting individuals and their families in the community. The rationale behind identifying these component based working groups can be found in Appendix B.

The Integrated Hospice Palliative Care Planning Council was formed on behalf of the Champlain HPEOLC Network to lead the model development process and included the chairs from each working group. The selection of working group chairs did not focus on organizational or geographical representation from Champlain, but was based on their sectoral knowledge of HPC and skill sets associated with systems level planning. The Planning Council met regularly to track all project related activities and provided support and direction to the working groups. The Terms of Reference and membership of the Planning Council can be found in Appendix C.

Once individual reports from the working groups were received, the Planning Council's efforts focused on the consolidation of the sectoral findings into a regional view for hospice palliative care for presentation to the Champlain LHIN. The original reports from each of the working groups contain a detailed review of specific system components. In addition to informing the development of the regional systems model, these reports and related recommendations will be invaluable when moving forward with implementation. A table highlighting all Working Group recommendations can be found in Appendix D.⁵

4. STAKEHOLDER ENGAGEMENT

Stakeholder engagement is recognized as an important part of the HPC model development process. Community engagement is also a primary objective of the Champlain LHIN (and a legal requirement as defined in the Local Health System Integration Act 2006). The draft plan for HPC, as presented in this report, has been shared with more than 300 stakeholders through 20 facilitated sessions (4 of which were organized for individuals, their family members and volunteers of day hospice programs involving more than 50 participants) as well as distribution

⁵ Individual working group reports are available upon request and will be appended to the final document submitted to the LHIN .

of the draft Plan and a SurveyMonkey questionnaire via email and on the Champlain LHIN website, in English and French, to solicit feedback from anyone interested in providing feedback.⁶

Throughout the consultation process, there was general support with the direction described in the Regional HPC Program Plan. There was recognition for the need to address the current challenges in the system with respect to the lack of service coordination and the need for integrating mechanisms to ensure individuals and their family members have access to the range of services they require in a timely manner delivered by competent service providers. At the same time, there was a strong message to ensure that aspects of the system that are working well, be sustained. Stakeholders also identified the need for ongoing consultation as additional details of the Program are fleshed out and operational decisions are made.

“My main problem was a lack of info - no-one told me about services. Everything was compartmentalized”
Hospice Day Program Client

The Stakeholder Engagement Plan and document summarizing the comments received from the community engagement process can be found in E and F respectively. This summary also includes a description of how the Regional HPC Program will responds to the issues raised.

5. TARGET POPULATION

It was clear from the outset of this planning initiative that the regional plan must demonstrate a benefit to the individuals in need of services. This includes not only the individual with the progressive, incurable illness, but also the family members and informal caregivers who are very much part of the individual’s journey and who play a significant role in enabling individuals to stay at home as long as possible.

“The majority of patients do not speak up and therefore, we need something in place – something to encourage us to have a voice.”
Hospice Day Program Client

⁶ SurveyMonkey produced 34 responses in English and 5 in French. The English comments originated with Palliative Providers (8), Other Service Providers (20) and the General Public (6). Three Service Providers completed the survey in French. It should be noted that the French survey was available for a shorter period of time than the English version.

This section of the document attempts to describe some of the distinctive client groups and other characteristics of the population in the Champlain Region that need to be included when planning for service delivery within the context of a new Regional HPC Program.

Pediatric Population

It is recognized nationally that only an estimated 10% of children/youth and their families have access to comprehensive palliative care services. In reports from 2002 and 2003^{7,8}, there were approximately 400 children/youth living with a progressive life-limiting condition in the Champlain region. On an annual basis, there are approximately 180 deaths from all causes among children/youth ages 0-19 (including infant deaths) in the Champlain region. Among children/youth ages 1-19 in Ontario, approximately 50% of deaths can be attributed to progressive life-limiting conditions such as neoplasms, congenital abnormalities, neurological disorders and endocrine/metabolic diseases. These rare and complicated diseases require specialized expertise, training and care. A specialized approach for bereavement is also a consideration for pediatric HPC services.

In Champlain, the majority of HPC services for the pediatric population is coordinated through the Children's Hospital of Eastern Ontario and Roger's House. Many of these services operate as a parallel system; however there is a need to ensure coordination to address integration issues for older youth who will be transitioning to the adult services. Integration also makes sense in the areas of research, education and advocacy.

Additional Considerations

There are a number of factors with respect to the geography of the Champlain region and to the people who live in the catchment area that need to be considered more specifically when planning system re-design. Some of these considerations, captured below, recognize that there are marginalized populations as well as individuals living with certain conditions who present with particular HPC challenges that will require special attention. **French Language Services**

⁷ Health Information Partnership Eastern Ontario Region. The Health Status of Children and Youth in Eastern Ontario. Kingston, Ontario, March 2002.

⁸ Health Information Partnership Eastern Ontario Region. Mortality in Eastern Ontario, 1986-1999. Kingston, Ontario. September 2003.

2006 Census data reveals that approximately 20% of residents in Champlain (228,000) chose French as their Mother tongue.

Geographical Considerations

- Physical size of catchment area – a large and diverse region encompassing 18,000² kms
- Rural and remote zones – many residents of Champlain live in areas where there are limited local care options. This often results in travelling long distances to access services

Demographic and Population-based Considerations

- French-Speaking Residents - Based on 2006 Census data, the Champlain region has 228,000 Francophone residents (approximately 20% of the region's total population).⁹ The proportion of francophone residents is much higher in Ottawa East (33.1%) and Eastern Counties (42.0%). Being able to receive palliative care services in one's language of choice (English or French) is an important component of access and is one of the priorities of the Regional HPC Program.
- Aboriginal Residents - 1.4% of the Champlain population identify themselves as aboriginal. The region includes the Akwesasne reserve (home to more than 10,000 aboriginals) and the Algonquins of Pikwakanagan (a smaller aboriginal community in Renfrew County)
- Persons with Dementia – An increasing number of individuals are dying with dementia, however dementia is often under-recognized as a life-threatening illness. From a care delivery perspective, the condition presents many challenges with respect to assessing, monitoring and measuring pain and other symptoms as well as overall prognostication. There is a need for an improved understanding of the course of the disease, end stage symptomatology and the role of HPC for individuals and families.
- Developmentally Challenged – The life span of individuals with developmental delays has increased substantially over the years as a result of continued advances in health technology and life-prolonging treatments. Consequently, this special population now faces many of the same chronic illnesses as the general population. HPC must take into consideration the unique needs of this population stemming from challenges associated with impaired social functioning and decreased ability to comprehend new and complex information.
- Homeless – Individuals who are homeless have a much higher mortality rate than the population in general. The provision of HPC for this population requires a specialized approach given that many homeless individuals are coping with additional challenges including a high rate of dependency on drugs and alcohol as well as living with mental illness
- Utilization of Services by Quebec Residents- Residents of Western Quebec frequently access both primary care and specialist services within the Champlain catchment area.

⁹ This includes individuals with a first language other than French or English, but who have identified French as their functional language in Canada.

- Multicultural Population - Approximately 14% of the population in Champlain identify themselves as a visible minority. Linguistic and cultural needs must be taken into consideration when providing HPC to new Canadians.
- Military Personnel – it is estimated that there are more than 10,000 military personnel in the City of Ottawa. The town of Petawawa has grown significantly over the last decade and is currently home to 5,100 military personal and an additional 7,700 military family members.

6. EVIDENCE IN SUPPORT OF A REGIONAL APPROACH

Regional palliative care programs

The introduction of a regional palliative care program in Edmonton in 1995 had a significant reduction in overall costs of care and reduced the number of cancer deaths in the acute hospitals from about 80% to about 35% (Bruera, 1999). This Program consisted of a single administrative body, the implementation of 40 hospice beds (3 hospices situated in long term care facilities so as to reduce the capital costs of building new hospices and using hospice appropriate staffing), sufficient acute palliative care beds, a strong primary health care component with the involvement of family physicians, and specialist palliative care consult teams in the community and in the hospitals. Implementation of this regional the palliative care services initiated a specialist service to support primary care and home care and reduced the costs of caring for an individual in the last year of life from \$30,000.00 a year to \$25,000.00- a significant cost saving to the system if one adds up the thousands of persons that die a year from their illnesses. Most of the savings were through the reduction of deaths in hospitals.

A report by Fassbender et al. looking at the effects of the introduction of a system-wide palliative care program in Alberta (specifically Edmonton and Calgary) between 1993-2000 showed that the implementation of a comprehensive and integrated community-based palliative care service provided better access to palliative care resources without increased costs to the health care system (Fassbender, 2005). The costs associated with the introduction of palliative care programs were offset by cost savings realized when terminally ill individuals with cancer had reduced length of stay in acute care hospitals. The total number of days that individuals remained in hospital during the study period dropped from 39.1 to 32.3 days. As well, during the study period, acute care costs declined from 83% to 68% of total individual health care costs in the last year of life.

In Spain, the development of a regional program and all its resources in the provinces of Catalonia (Barcelona) and Estremadura resulted in significant savings to the health care system through reduced use of emergency rooms, earlier discharges from the acute care sector and reduced deaths in the acute hospitals (Gomex-Batiste et. al. 2005, Gomex-Batiste et. al. 2006, Paz-Ruiz 2009).

In-hospital palliative care consultation teams

The beneficial effect of palliative care consultation teams on symptom control is generally accepted and has been demonstrated in multiple studies world-wide (Morrison et.al. 2008, Braiteh et. al. 2007, Hauptman et. al. 2005). The benefits include improved end-of-life care, increased discharges from hospital, improved patient satisfaction and reduced hospital costs. A 2003 analysis of 44 different studies looking at effects of palliative care showed that evidence supports the positive effect of palliative care teams on symptom control with the most significant improvement often seen with pain (Higginson, 2003).

A 2007 study at a large Cancer Center showed that while the referring team had mentioned on average one symptom per individual in their consultation request to palliative care, the consultation team identified a median of 8 symptoms and problems per individual. The identification and treatment of previously unrecognized and untreated issues, such as delirium, psychosocial issues, and opioid-related side effects resulted in rapid symptom improvement (28% of individuals showed improvement within 24 hours, and another 38% within 72 hours).

A 2004 study for the Manitoba Centre for Health Policy found that 21% of the province's health care costs were consumed by people in the last 6 months of life, who occupied 24% of hospital beds (Menec). Palliative Care Programs reduce hospital and ICU expenditures by clarifying goals of care and assisting individuals and families to select treatments that meet those goals. In the ICU setting, palliative care consultation services have been shown to reduce the length of stay (LOS) in the Intensive Care unit (ICU) (Sally, 2007). Individuals receiving palliative care consultations were also less likely (up to 42% in one study) to be admitted to the ICU during the hospitalization (Penrod, 2006).

Palliative care consultation services have been shown to decrease hospital costs in two ways (Smith 2009):

1. Cost-avoidance: Shows how palliative care can save money to the health care system even if the unit is not profitable itself. Example: when an individual is transferred from ICU (3500\$per day) to the PCU (1500\$ per day), it equals savings of 2000\$ per day.

2. Opportunity cost: Demonstrates the additional revenue that could be gained if money had been used in a different way. Example: an ICU bed that is filled with someone who is not going to get better may cause backlog into the ER, increasing LOS in ER. If a palliative care program assists in the transfer of 200 ICU patients 2 days earlier, then the medical staff will have 400 more ICU bed days available.

Palliative care consultations result in more appropriate use of therapies, treatments, and investigations creating a decrease in variable costs. In one study, the more proper allocation of resources was demonstrated by the fact that, following palliative care consultations, 58.1% of individuals/families decided to forego burdensome, unwanted, unnecessary, and costly treatments, not including the 46 cases where the decision was to forego resuscitation in individuals who expired during the hospital stay (who could have therefore been ICU transfers) (Manfredi, 2000).

Costs of End of Life Care

Costs vary considerably depending on many factors, including the place of care and death, resources used (for example, emergency rooms, acute care hospital, home care or hospice care, and the health care system). *It is important to note that available data on costing focuses mainly on the end of life care portion of the individual's journey.*

A recent study comprehensively assessed the total societal costs of home-based palliative care in metropolitan Toronto (Denise, 2010). These costs included the costs to the public system, private costs to the individual and their family, and third party costs, as well as leisure time lost to the family. One hundred and thirty-six family caregivers were interviewed every two weeks from time of palliative referral until death. Information regarding appointments, travel and out-of-pocket expenses, time devoted to caregiving and caregiver lost time from the workplace, as well as demographic and clinical characteristics were measured. The mean monthly cost of care per individual was \$24,549 (2008 CDN\$). Family caregivers' time comprised most costs (70%).

Costs were greater for individuals: who had lower physical functioning ; who lived with someone; and who were closer to death.

Leong and colleagues (2007) examined the magnitude and determinants of the share of private costs incurred by Ontarians who received in-home publicly financed services and by their unpaid caregivers. The private share of costs was found to be 75%. recipients of home-based health services in Ontario may bear an economic burden when care is shifted into the home setting.

The systematic implementation of advance directives in nursing home has been shown to reduce hospitalizations per resident and less resource use than in nursing homes that did not implement such plans (Molloy, 2000).

Utilization of Emergency Rooms

For individuals dying of cancer, a visit to the emergency department can be disruptive, distressing and exhausting. Such visits made near the end of life are considered an indicator of poor-quality cancer care. Dudgeon and colleagues recently studied the most common reasons for visits made to the emergency department in Ontario during the final six months of life and the final two weeks of life by individuals dying of cancer. Between 2002 and 2005 in Ontario, 91,561 individuals died of cancer. Of these, 76,759 individuals made 194,017 visits to the emergency department during the final six months of life. Further, 31,076 individuals made 36,600 visits to the emergency department during the final two weeks of life. Of those who visited the emergency department during the final six months of life, 36.5% made one visit, 26.8% made two, 15.9% made three, 8.9% made four, 4.9% made five, and 6.9% made six or more. The most common reasons were abdominal pain, lung cancer, shortness of breath, pneumonia, fatigue, and pleural effusion (fluid in the chest cavity causing shortness of breath). The investigators concluded that many visits made to the emergency department by individuals with cancer near the end of life may be avoidable.

Another recent study demonstrated that individuals with Lung cancer are heavy users of acute care beds and the emergency room at the end of life (Barbera 2008). In total, 5,855 individuals who died of lung cancer in 2002 were included in this Ontario-based study. Rates of in-hospital death, emergency room visits, intensive care unit admissions, and chemotherapy use near the end of life were 59.5%, 32.2%, 5.5%, and 4.6%, respectively. The investigators concluded that

the results suggest that the quantity and quality of their care was not sufficient to address their needs or the needs of their caregivers. Instead, these individuals require either additional support to remain at home or direct transfer to a palliative care unit or residential hospice, or a combination of these. Other studies have shown that the involvement of family caregivers and family physician visits reduced the likelihood of admissions to the emergency room (Burge 2003, Gomes 2006).

Home Care

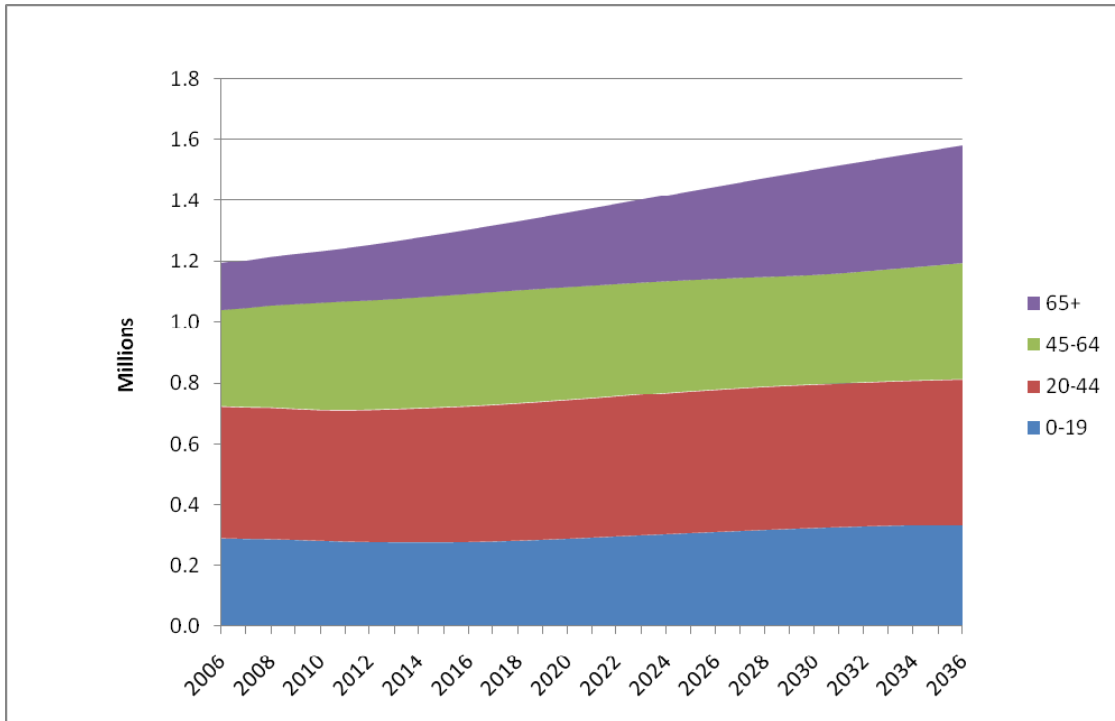
Hsien and colleagues (2010), in a recent study looking at individuals admitted for end of life home care in Ontario, found that the 9018 individuals included in the study used an average of 3.11 nursing hours/wk, 3.18 personal support and homemaking hours/wk, and 18% were admitted to homecare for <1 month. Individuals admitted earlier than 6 months before death had a 35% lower chance (odds ratio) of hospitalization than those admitted 3 to 4 weeks before death. Individuals using more than 7 nursing hours/wk and more than 7 PSW h/wk had a 50% and 35% lower chance (odds ratio) of a hospitalization, respectively, than individuals using 1 h/wk.

In another Canadian study, investigators prospectively examined individuals and their family caregiver preferences for location of death of individuals hospitalized with cancer and end-stage medical conditions (Stajduhar, 2008). Questionnaires were administered to 440 eligible in-patients and 160 family caregivers. Half of all individuals and their family caregivers report a preference for a home death. Furthermore, half of the individual/family caregiver dyads disagree on preferred location of death. The investigators concluded that If one of the primary goals of end of life care is to enhance the quality of life of dying individuals and their family caregivers, policies directed towards ensuring that individuals die in their location of choice ought to be a priority and resources should be allocated to promote the development of excellent care, not only in the home, but also within institutional settings. This would include adequate access to palliative care units and hospices for those individuals who prefer not to die at home or for whom dying is not possible.

An Aging Population

Demographic projects for the Champlain Region, as depicted in Figure 1, show that the proportion of people over the age of 65 is rapidly increasing. As the majority of deaths occur in this age group, it is anticipated that the demand for palliative care will increase substantially.

This is more clearly demonstrated in Table 1 which shows the anticipated increase in deaths related to cancer, heart failure, Alzheimer’s and Renal Disease for individuals over the age of 65 yrs.¹⁰ An increasing focus on palliative care is necessary to ensure the health care system in a position to meet the forecasted demand.



**Figure 2 Population age projections in three age groups.
Source. Ministry of finance projections.**

Table 1

Diagnostic Category	2005 Actual Deaths	2035 Projected Deaths
Cancer	1,879	4,812
Heart Failure	825	2113
Alzheimer’s Disease	441	1,129
Renal Disease	114	292
Total	3,259	8,346

Source: Champlain LHIN

¹⁰ Projections show that there was not a significant anticipated increase for deaths in these diagnostic groups for younger age groups

Figure 2 (below) based on actual cancer and non-cancer lead cause groups death in 2005 reveals some interesting trends. The incidence of non-cancer related deaths increases dramatically with age and is particularly prevalent among the 75 – 90+ age groups. There is also an increase as people age, although less dramatic, in the number of cancer deaths. These statistics demonstrate the importance of addressing the palliative care needs of individuals with non-malignant, chronic illness. The application of Johanne Lynn’s model (Lynn 2002) assists in the identification of individuals who would benefit from a palliative care approach.

2005 Cancer Deaths and Non-Cancer Lead Cause Groups

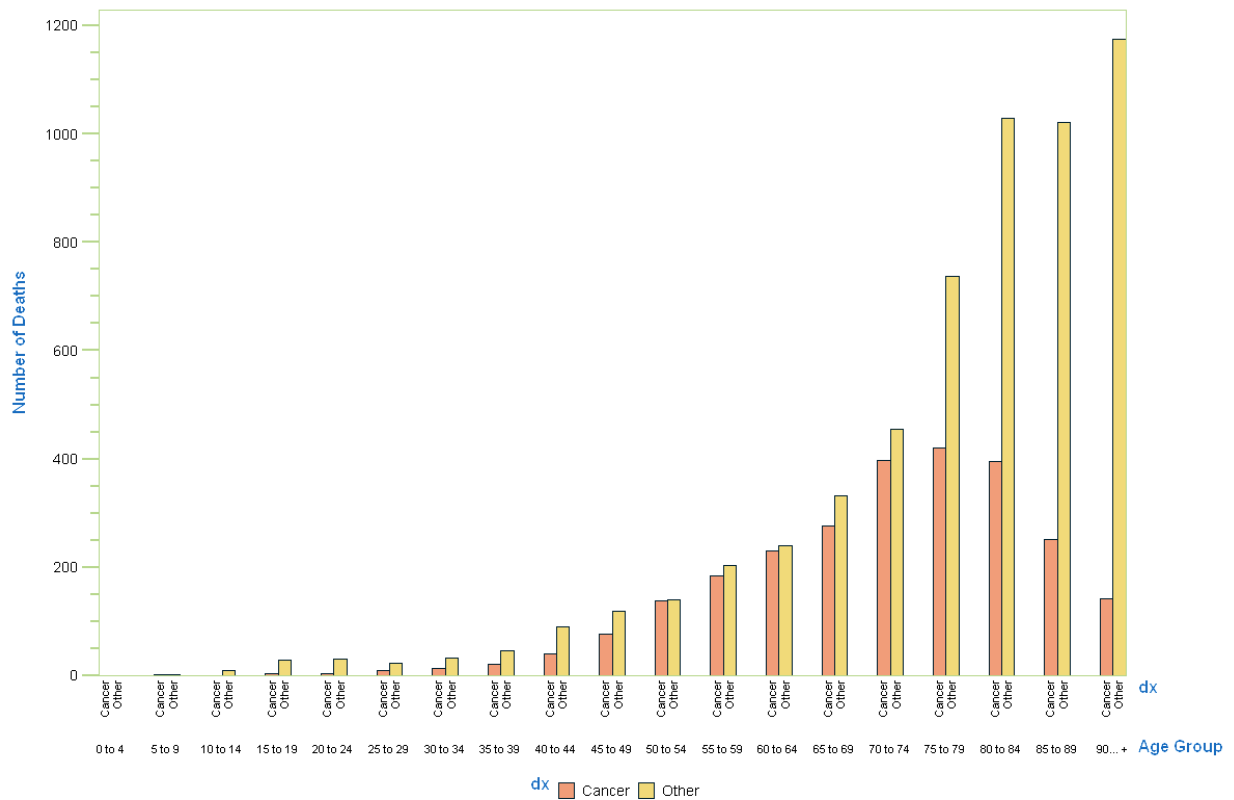


Figure 3 2005 Deaths. Detailed age groups, divided by cancer and non cancer lead cause groups
 Source: PHPDB Deaths Table 2005.

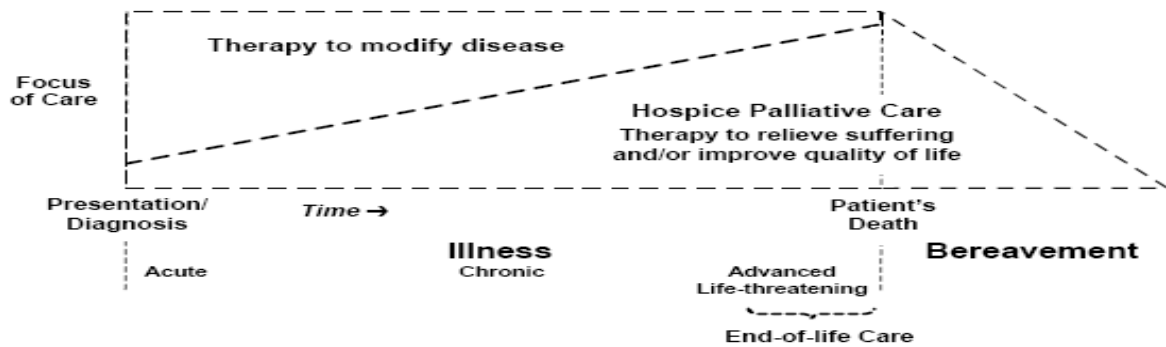
7. FOUNDATIONAL COMPONENTS

Canadian Hospice Palliative Care Association Model

In 2002, the Canadian Hospice Palliative Care Association (CHPCA) released its framework document to guide all activities related to hospice palliative care in an attempt to address the

variability in the quality and availability of HPC.¹¹ The CHPCA Model, depicted below, is the generally accepted model describing HPC in Canada. Therefore, it has been adopted by the Planning Council for the regional planning process. The model is designed to describe the role of hospice palliative care during illness, depicting the typical shift in the focus of care over time. The dashed diagonal line attempts to distinguish interventions intended to modify disease from interventions intended to relieve suffering and/or improve quality of life (labeled hospice palliative care).

Some working group participants expressed concern that this definition does not adequately reflect the less predictable illness trajectory for non-malignant diseases where the individual's condition may have many acute episodes from which they recover. For individuals with end stage chronic diseases, acute episodes within the disease trajectory often mirror symptoms associated with end of life. While the palliative care approach may be appropriate during these episodes, the individual often 'bounces back' and returns to their previous state of functioning. The CHPCA document acknowledges that the lines are straight for simplicity, recognizing that in reality, the total 'quantity' of intervention and the mix of concurrent therapies will fluctuate based on the individual's and family's issues, their goals for care and treatment priorities.



Primary Care Service Delivery Model

Primary health professionals provide an important first-line level of palliative care. A fundamental component to the development of a regional program for Champlain is one that empowers, encourages and supports primary care providers to deliver HPC. Reliance on a plan

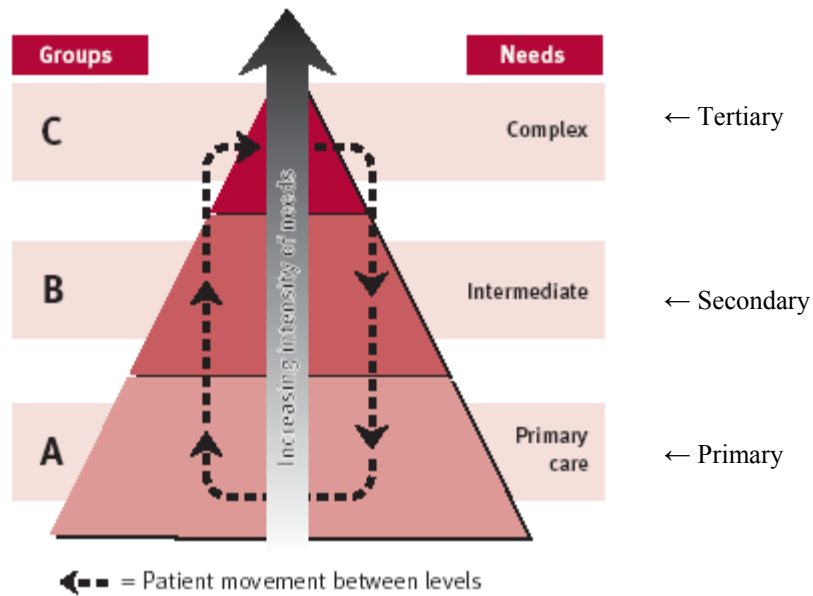
¹¹ *A Model to Guide Hospice Palliative Care (CHPCA 2002)*

which depends on HPC specialists to take over the care of individuals from family physicians with palliative experience is not sustainable in the long-term due to the availability of specialists and the related costs associated with this level of care delivery.

In the more successful regional palliative care programs, three levels of HPC are available, which include primary care, secondary care and tertiary care. The latter two usually represent palliative care specialist services, including consultation services. In Level A, HPC is provided at the primary health care level, usually by primary health professionals with the support of secondary or tertiary level specialized teams. Level B represents interventions by HPC consult services, usually in the support of primary teams or hospital attending teams. Level C (tertiary level), represents the smallest proportion of the services and consists of HPC experts with advanced education and skills in palliative care. This level is largely responsible for caring for the most complex cases and advancing the field academically through education initiatives and research. All levels are responsible for providing pro-active care that anticipates crises and attempts to put in place a process to prevent them or respond rapidly should they occur.

While many individuals may be adequately cared for by primary health professionals with basic palliative care competencies, others with more complex problems will require the interventions of specialized palliative care services. Sometimes these interventions may be temporary, while in other cases the individuals may require the ongoing care of these specialist teams. The diagram below, an extract from the Australian National Palliative Care Strategy, illustrates the three levels. Palliative care at a primary level represents the largest proportion of service provision.¹²

¹² Palliative Care Australia, <http://www.palliativecare.org.au>. This model is used extensively in Australia and Ireland.



It is important to note that a wide array of community services exists to support the individual and their family in their homes. These services, which are delivered by both health service professionals and volunteers, provide much needed respite, emotional support and assistance with home management to individuals and their families both in their home and in day program settings. Without these services, the professional care needs of individuals requiring HPC would likely increase significantly. However, there is currently no standardized program of training across Champlain region for these volunteers.

8. GUIDING PRINCIPLES FOR PROGRAM DEVELOPMENT

The principles, described below, will be used as an ongoing tool to promote and support the Planning Council’s vision of an integrated, regional hospice palliative care program in our region, and ultimately, influence the way services are developed and offered across Champlain.¹³

The Planning Council supports the development of a regional system that:

- recognizes the importance of a holistic, person and family-centred approach to care that addresses the spiritual, cultural, social and bereavement needs of Champlain's diverse population and in particular the Francophones and First Nations' people

¹³ The planning principles have been developed using a number of sources, but are largely based on the principles and norms found in the CHPCA’s: A Model to Guide Hospice Palliative Care (2002).

- recognizes primary care as a foundational component with strong linkages to secondary and tertiary levels of care.
- empowers and supports primary care providers in the delivery of HPC.
- promotes comprehensive, timely and equitable access to HPC services for all people based on person and family needs - independent of factors such as diagnosis, age, language, cultural background or geography
- decentralizes services where possible and centralizes services where necessary
- demonstrates a cost effective and sustainable use of resources
- is based on available data, research and the application of best practices
- supports palliative care education and training of hospice palliative care service providers, volunteers, individuals, and families and the general public based on known standards and competencies
- is based on an inter-professional team approach to service delivery
- incorporates performance measures to support ongoing evaluation and quality improvement.
- supports the implementation and application of research and the transfer of knowledge
- builds on the existing strengths of the system
- incorporates community engagement and community consultation when planning for new services and/or service modifications

9. RECOMMENDATIONS

The following section highlights the Planning Council's recommendations to support the development of a Regional HPC Program for Champlain. The recommendations are framed around the 'key elements' of a system that, according to the national and international literature from Edmonton (Bruera 1999), Calgary (Fassbender, 2005), Spain (Gomex-Batiste, 2007 and 2006) and Australia (Palliative Care Australia, 1998), lead to the success of a regional program. Interestingly, there is significant agreement between the priority areas supported by the literature and those identified at the Champlain HPC Retreat (April 2009) with both supporting that an integrated approach requires that services need to be organized differently.

Within each Key Element, priority recommendations have been identified that address the most pressing system issues and gaps related to HPC.

Champlain Regional HPC Program: Key Element #1

A Common Region Wide Vision and Mission For Hospice Palliative Care In Champlain

....so that all providers are working with individuals and their families toward the same goals

Priority Recommendation:

A Regional HPC Program be established in Champlain

The goal of establishing a Regional HPC Program is to ensure HPC individuals requiring HPC and their families have access to a coordinated, accessible and accountable palliative care service delivery system in the Champlain region. In order to assist in articulating a Champlain-wide plan for HPC, members

“There has to be better communication between hospitals and the community”
Hospice Palliative Care Volunteer

of the planning council recognized the need to develop a vision and mission. The draft vision being put forward for discussion, as expressed below, describes the program in the future and responds to the question “Where are we going?” while the mission/mandate describes the overall purpose “Why do we exist?”

Vision

Residents of Champlain have access to the right care, at the right time, in the right setting by the right provider based on their HPC needs.

Mission

To provide a sustainable, integrated and coordinated person and family centred regional system of HPC in Champlain

Champlain Regional HPC Program: Key Element #2

A Leadership/Governance structure to provide direction, manage and address issues of accountability and sustainability for the new Regional HPC Program as well as conduct strategic planning and ongoing community engagement

..... to be accountable for a Program that meets the needs of individuals and their families

The centralization of leadership/governance is an important element of a regional strategy. This will offer the necessary infrastructure to support the Regional HPC Program by providing a means for collaborative, transparent priority-setting and integration of planning across all system components.

“The first step is information to getting control of your life back”
Day Hospice Client

Priority Recommendations:

A Regional Hospice Palliative Care Leadership Committee be established to oversee the Regional HPC Program.

The Leadership Committee will establish formal agreements with HPC providers to support the objectives of the Regional HPC Program to incorporate service delivery standards and competencies as well as to establish performance indicators for evaluation and program planning.

This Body will report to the LHIN and will develop a work plan to reach the following objectives:

- To identify service integration and coordination priorities within the system
- To ensure the engagement of francophone and first nations people in the development of culturally and linguistically appropriate services
- To make recommendations to the LHIN on the budgetary allocation and re-distribution of resources in collaboration with service provider agencies and the LHIN
- To develop a regional HPC bed plan for Champlain
- To establish an accountability agreement or other formal agreement with the LHIN
- To establish formal agreements with HPC providers
- To develop and disseminate standards in the areas of clinical competencies, service delivery and education
- To identify and inform the research community of regional research priorities
- To monitor and evaluate service delivery and report on performance to the LHIN
- To ensure effective and efficient community engagement at the Program and service level

- To ensure the integration of demographic and population-based considerations as part of program implementation (i.e. pediatric population, multicultural population, homeless, persons with dementia)
- To establish *community of practice* sub-committees to support the work of the Council

Supporting Recommendations:

- Membership on the Leadership Committee will be based on the skills and competencies of the individuals rather than organizational representation thereby connecting with broader HPC service sectors. In keeping with the mandate of the LHIN, this would also include individuals with knowledge of the francophone¹⁴ and Aboriginal / First Nations people.

Champlain Regional HPC Program: Key Element #3

Access to Information and Services

... so individuals and their families and all providers have somewhere to go for additional information on what services are available

The wide array of services, number of service provider organizations and other complexities within our health care system often leave individuals and their families uncertain about services available to them and how to access these important resources. In addition, service providers are often unaware of the range of available services and how to assist individuals in accessing what they need. Assistance in navigating the system is a clear priority.

“When I was asked by a nurse if I wanted to see a Social Worker, I didn’t know why I would want to see one. I didn’t have information about what they did”
Day Hospice Client

Priority Recommendations:

- **Establish a comprehensive, accessible information system initially focused on HPC related services for individuals, family members and professionals to assist with system navigation**
- **Establish and communicate clear criteria for access to HPC services**

¹⁴ The French Language Health Services Network of Eastern Ontario (Le Réseau) is identified as the main partner representing the francophone community in the Champlain area.

Supporting Recommendations:

- Ensure service providers have a clear understanding of the individual's journey and access to the support and knowledge transfer to assist the individual with navigation.
- Explore the establishment of a model based on 'sub regional hubs' as a means of bringing care closer to home and to better support community-based service providers
- Develop electronic access to information and patient database/registry in HPC building on existing work Champlain and in keeping with the LHIN e-health strategy.
- Promote and build on the information sharing capacity of the Chart in the Home recognizing this paper-based tool will assist in identifying the important components for a database
- Define the system's transition points, identify information that needs to be shared and standardize the means of transferring information (these steps should contribute to reducing duplication associated with gathering information).
- Expand the use of e-health/tele-health and other technologies in HPC for service delivery and education

Champlain Regional HPC Program: Key Element #4

An Adequately Resourced System

..... to ensure services are available to individuals and their families when and where they are needed

One of the key components to ensure the success of a regional model is to ensure that the system is properly resourced so that the necessary range of services is available to the individual with a progressive incurable illness and their family, and can access these in a timely manner.

"It is financially cheaper to keep me at home"
Day Hospice Client

Priority Recommendations:

- **Recommend funding allocation and realignment of resources to the Champlain LHIN following thorough analysis of current resources and system gaps.**
- **Develop a regional HPC bed plan which will include a realignment of resources from the acute care sector.**

Supporting Recommendations:

- Review current service components to identify and eliminate the unnecessary duplication of services
- Explore existing and creative funding models of core services to achieve cost effectiveness and ensure sustainability (i.e. funding models for residential hospices)

Champlain Regional HPC Program: Key Element #5

Evidence-Based Care and Best Practice

....so services delivered to individuals and their families are based on available research and are the most effective known

The application of HPC evidence-based care and best practices are important techniques to improve the effectiveness and efficiency of service delivery. A region-wide approach will ensure the delivery of quality care to individuals and their families across Champlain.

Priority Recommendations:

- **Develop and implement a strategy for enhancing HPC in LTC Homes**
- **Develop strategies to ensure there is adequate access to secondary and tertiary consultation teams in the region's hospital, hospices, LTC Homes and the community.**

Supporting Recommendations:

- Develop strategies to ensure individuals and families have access to inter-professional team of service providers at the primary, secondary and tertiary levels.
- Adopt, adapt or develop common validated tools (e.g. decision support tools, pathways, assessments list others) that address the needs along the continuum
- Identify current best practices and evaluate them for common use across the system
- Establish a common approach to HPC including the use of common language (e.g. palliative care vs supportive care) along the entire continuum of needs.

Champlain Regional HPC Program: Key Element #6

Common Reporting/Data Collection and Performance Indicators

....to know through evaluation that the Program is continuing to meet the needs of individuals and their families

The ability to evaluate the delivery of HPC to residents of Champlain is dependent on the availability of data. At the present time, there are no data collection standards or consistency of data collection between organizations.

Priority Recommendations:

- **Establish specific system and provider performance measures for ongoing system planning, monitoring and surveillance to be incorporated into accountability agreements with the Champlain LHIN**

Supporting Recommendations:

- Establish a standardized minimum data set to support Program reporting and evaluation (i.e. using balanced scorecard approach addressing financial, customer service, internal processes and learning/growth).
- Develop strategies to ensure this approach is consistent with the LHIN performance measurement systems (including data focused on French language indicators)

Champlain Regional HPC Program: Key Element #7

A Strong and Well Supported Primary Care Service Delivery Model

...to assist and encourage family physicians and others in providing HPC services to individuals with progressive, incurable illness and their families

As the population ages and the need for HPC continues to increase, so does the need to ensure that good, basic HPC provided by family physicians and other primary health professionals is available to individuals and their families. As a foundational component of the regional plan, the system needs to ensure the necessary supports to make this happen including an adequate number of primary care professionals, fair remuneration, and education and support from specialist services. With appropriate support from specialist consultants, studies have shown that primary care professionals are able to deliver sound and effective palliative care.¹¹

Priority Recommendations:

- **Implement a service delivery program with a strong primary care basis supported by secondary and tertiary level palliative care expertise**

Supporting Recommendations:

- Implement innovative models to providing timely access to primary palliative care services in settings where there is a lack (i.e. LTC homes)

- Build capacity in the system through clinical support, mentoring and education in all primary care type settings (e.g. RNAO Family Practice Nurse Interest Group, hospices, nurse practitioners, home through community support services)
- Strengthen and broaden the current secondary level support services to support primary care services.
- Develop strategies to assist people who do not have a family physician or primary care provider in obtaining primary palliative care

Champlain Regional HPC Program: Key Element #8

Standards and Competencies

..... to ensure individuals and their families have access to quality care across the system

The implementation of standards and competencies contribute to the delivery of consistent, quality HPC care.

Priority Recommendations:

- **Develop service delivery standards and competencies that will be incorporated into agreements with HPC providers**

Supporting Recommendations:

- Encourage agencies providing HPC to have status of accreditation or equivalent (e.g. accreditation body, legislative standards, college)
- Identify core competencies for HPC providers at each level (primary secondary tertiary)
- Establish processes to monitor the consistency of care delivered in all settings including core competencies as an effort to ensure members of the inter-professional health care team have the knowledge and skills to provide quality palliative care in the community.

Champlain Regional HPC Program: Key Element #9

Education, Knowledge Transfer and Research

..... to ensure everyone involved in HPC, including individuals, their family member, service providers and volunteers, has access to a standardized education program and resources to expand their knowledge.

Priority Recommendations:

- **Develop a standardized regional strategy for HPC education for stakeholders**
- **Expand the use of e-health/tele-health and other technologies to support care delivery and education, particularly in rural and remote regions**

Supporting Recommendations:

- Improve linkages with community support agencies to better integrate these services and to ensure individuals have earlier access to HPC services.¹⁵
- Seek out opportunities to provide HPC education to other provider groups that have HPC clients, but may not have the specific HPC expertise.
- Provide education on changing practices/regulations (e.g. fee structures for family physicians).
- Develop strategies to link with other research bodies in Champlain and translate knowledge to practice (e.g. adapt heart institute technology)
- Identify research priorities for the region

10. PROGRAM IMPLEMENTATION

Workplan

There are a number of important steps that need to take place in order to move us closer to the establishment of a Regional Hospice Palliative Care Program for Champlain. The implementation work plan outlined in this section of the document focuses on a number of key objectives that need to be addressed within the first year. A draft gantt chart and budget outlining anticipated costs for operationalizing the Program follows. Objectives for Year 1 include:

- To manage the transition as we move to the proposed Regional Program
- To establish a Leadership Council for the new Regional Program
- To begin to address priority recommendations as outlined in the Regional Plan
- To address the current crisis issue related with residential hospices
- To develop a strategic and longer-term workplan to advance the recommendations put forward in the Regional Program Plan

¹⁵ The CSS sector has been providing services to HPC clients and those with chronic illness as part of the routine services offered to all clients. There has not been a formal consideration regarding how to provide these services in the context of HPC. This would require a shift in resources and education of staff, volunteers and others involved in these services.

Objective #1: To manage the transition to the new Regional Program (Months 1-4)

Action Steps/Activities	Considerations	Timeline
Establish a Transition Group	<p>Member competencies will include:</p> <ul style="list-style-type: none"> ▪ Knowledge of health care systems ▪ Knowledge of /experience with Program Development <p>Membership:</p> <ul style="list-style-type: none"> ▪ Clinical representation with knowledge of HPC system ▪ Representation with experience in regional program development ▪ Medical representation ▪ Representatives from the Planning Council ▪ Le reseau ▪ Aboriginal Health Circle <p>Objectives would include:</p> <ul style="list-style-type: none"> ▪ To develop Terms of Reference for the Leadership Committee ▪ To develop job description for Program positions ▪ To identify competencies and proposed inaugural membership of the new Program Leadership Committee ▪ To develop a draft agreement between the Leadership Committee and the LHIN ▪ To obtain targeted feedback regarding the transition process ▪ To ensure the functional essence of the current Network (what is working well) is not lost ▪ To manage other transition related issues 	June 2010 – September 2010

Objective #2**To establish a the Leadership Committee for the new Regional HPC Program (Month 5)**

Action Steps/Activities	Considerations	Timeline
Secure membership for the new Leadership Council and organize initial meeting	As per the recommendations of the Transition Group	October 2010

Objective #3**To identify priorities for the new Regional Program and begin implementation (Month 6-12)**

Action Steps/Activities	Considerations	Timeline
Approve TOR for Leadership Committee		October
Establish the Regional Program Office		November
Establish TOR, membership and workplans for 'communities of practice' subcommittees		December
Develop program budget		December
Finalize accountability Regional Program agreement with the LHIN		January
Establish a plan for ongoing stakeholder engagement		January
Initiate website development		February 2011
Continue to build on the environmental scan for HPC in Champlain		February 2011
Identify system standards and performance indicators aligned Program objectives /recommendations		March 2011
Recommend elements related to HPC that should be incorporated into existing HSP accountability agreements with the LHIN	Elements might include: <ul style="list-style-type: none"> ▪ Agreement in principle with objectives of the Program ▪ Performance indicators ▪ Recognition and support for service standards including service provider competencies 	April 2011
Initiate the process to develop standards in each HPC element		Ongoing

Objective #4**To address the current crisis issue related with residential hospices (immediate and ongoing)**

Action Steps/Activities	Considerations	Timeline
To establish an integration plan for hospice beds in Ottawa.	<ul style="list-style-type: none"> ▪ This would include developing a proposal for consideration by the LHIN re: residential hospice in the Ottawa area 	May –August 2010
To examine residential hospice needs including service gaps in the rest of Champlain and make recommendations accordingly		September – December
To be involved in ongoing planning for residential hospice beds across Champlain		Ongoing

Objective #5

To develop a 3year strategic workplan for the Regional Program (ongoing)

Action Steps/Activities	Considerations	Timeline
Conduct a review of priority and supporting recommendations as outlined in the Regional Program Plan		October 2010– May 2011
Finalize a 3 yr workplan to guide the activities of the Leadership Committee and the Communities of Practice		May 2011

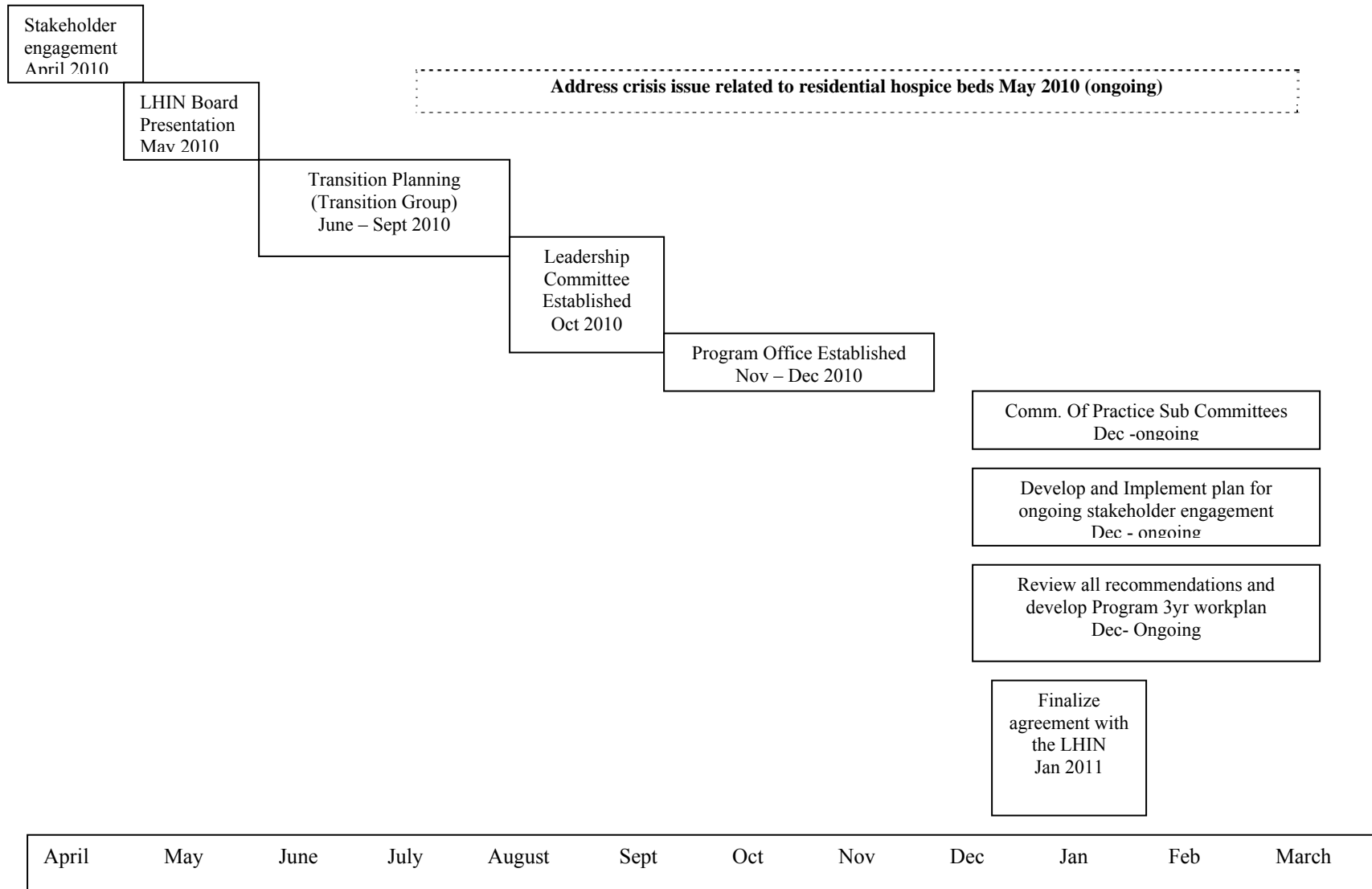
Estimated Program Management Budget

Human Resources ¹	Estimated Cost	Considerations
Program Manager ²	\$90,000	Full-time
Administrative Support	\$40,000	Full-time
Medical Lead	\$40,000	Part Time
Informatics Technician	\$65,000	Web development as well as exploring and implementing e-learning, tele-consulting and other new media for information flow
Decision Support	\$65,000	Data collection and analysis expertise
Operating Expenses	Estimated Cost	Considerations
Purchased Services	\$50,000	Funds for expert services on an as needed basis
Translation	\$40,000	
Meeting Expenses	\$5,000	
Travel expenses	\$10,000	Champlain-wide Program
Office Rental	\$20,000	Estimates - To be negotiated with 'host' agency
Phone, fax, computers, photocopiers etc.	\$8,000	
Office supplies	\$7,000	
Total	\$440,000	
Education	Current resources available in the system	

¹ Estimated costs for Program staff are based on a FTE and do not include benefits.

² This would be supported with the \$80,000 received from the MOHLTC for the Champlain HPEOLC Network Coordinator position.

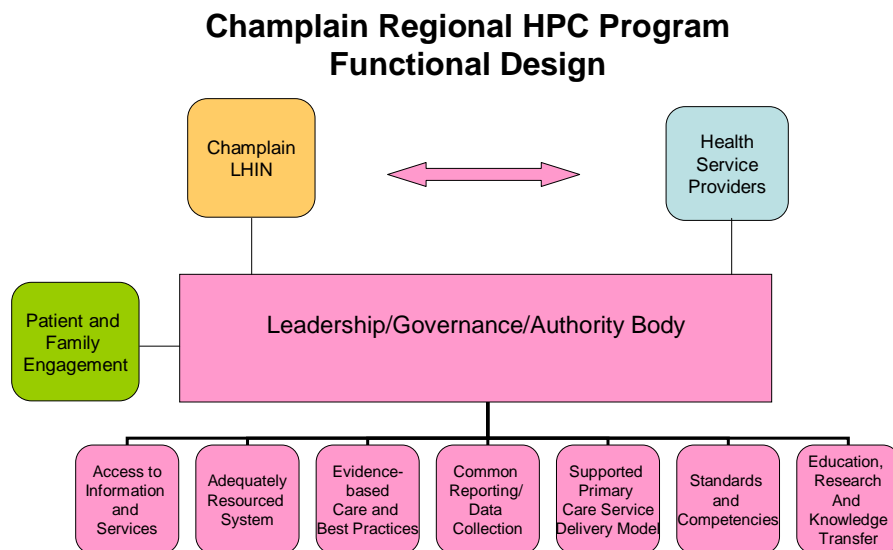
REGIONAL HOSPICE PALLIATIVE CARE PROGRAM YEAR 1 IMPLEMENTATION TIMELINE APRIL 2010 – MARCH 2011



11. SUMMARY

There is no doubt that in most instances, individuals in Champlain are receiving high quality palliative care services. However, there is significant room for improvement with respect to how these services communicate with each other and how they work together in order to ensure that care is being delivered to the right individual, at the right time and in the right setting. The plan presented in this document is designed to reduce, and eventually eliminate, the duplication and “silo” approach to planning and service delivery and ultimately result in improved access to quality hospice palliative care for residents of Champlain.

The diagram below provides a functional overview of the proposed Regional HPC Program. It demonstrates relationships among the Leadership Committee Body, service delivery organizations and planning bodies.



Providers of hospice palliative care in Champlain have a genuine willingness to work collaboratively to ensure the best possible health care experience for individuals and their families. However, in order to truly be able to work together toward in the best interest of

individuals with progressive, incurable illness, there is a need for the system to shift toward a more comprehensive and integrated service delivery model for palliative and end of life care. Health care organizations need to share a common vision for HPC so that all health care providers are working toward the same goal.

A summary of the recommendations put forward in this plan have been incorporated into the tables below. This summary demonstrates how establishment of a Regional HPC Program will work to improve the HPC service delivery system.

“This Plan makes a lot of sense and is long overdue – Unfortunately (because I am dying) I won’t see the changes in my lifetime”
Day Hospice Client

REGIONAL HPC PLAN RECOMMENDATIONS SUMMARY

FOUNDATIONAL COMPONENTS			
Key Element	Current State	Recommendations	Future State
1. Common, region-wide vision and mission	No common vision or mission for HPC	Priority Recommendations <ul style="list-style-type: none"> ▪ Establish a Regional HPC Program for Champlain 	Regional HPC Program with a common vision, mission, values and branding
2. A Leadership/ Governance Structure	'Siloed' approach to service delivery	Priority Recommendations <ul style="list-style-type: none"> ▪ The formation of a Leadership Committee to oversee the Program ▪ The establishment of formal agreements with HPC providers to support the objectives of the Program, to incorporate service delivery standards and competencies as well as to establish performance indicators for evaluation and program planning. Supporting Recommendations <ul style="list-style-type: none"> ▪ Develop a Terms of Reference ▪ Identify membership competencies ▪ Establish a formal agreement with the LHIN ▪ Develop an operational budget and workplan (3 year time-frame) 	High level of service coordination High level of collaboration Ongoing evaluation, quality control and improvement Regional strategic planning Coordinated approach to stakeholder engagement

SUMMARY PLAN			
Key Element	Current State	Recommendations	Future State
3. Access to information and services	<p>Multiple sources of information</p> <p>No coordinated approach</p>	<p>Priority Recommendations</p> <ul style="list-style-type: none"> ▪ Establish a comprehensive, accessible information system initially focused on HPC related services for individuals, family members and professionals to assist with system navigation ▪ Establish and communicate clear criteria for access to HPC services <p>Supporting Recommendations</p> <ul style="list-style-type: none"> ▪ Ensure a clear understanding of the individual's journey ▪ Determine the feasibility of 'sub regional hubs' ▪ Expand the use of e-health/tele-health and other technologies ▪ Continue to promote and build on the Chart in the Home ▪ Simplify the transition process 	<p>Enhanced coordination and simplified access to information and services</p> <p>Comprehensive repository of information</p> <p>Enhanced system navigation</p> <p>Establishment of regional 'hubs'</p> <p>Implementation of e-health strategies to support access to information</p>
4. A system that is resourced to meet the needs	<p>Lack of hospice, respite and long-term HPC beds</p> <p>No regional plan for HPC beds</p> <p>Inconsistent HPC in LTC Homes</p>	<p>Priority Recommendations</p> <ul style="list-style-type: none"> ▪ Recommend funding allocation and realignment of resources to the Champlain LHIN following thorough analysis of current resources and system gaps. ▪ Develop a regional HPC bed plan which will include a realignment of resources from the acute care sector. <p>Supporting Recommendations</p> <ul style="list-style-type: none"> ▪ Assess current resources Identify service gaps and areas of duplication ▪ Review funding models of core services to achieve cost effectiveness 	<p>Reduced duplication of services</p> <p>Collaborative approach to regional funding priorities</p> <p>Implementation of e-health initiatives to support care delivery in rural and remote regions</p>

SUMMARY PLAN			
Key Element	Current State	Recommendations	Future State
5. Evidence based care and best practices		<p>Priority Recommendations:</p> <ul style="list-style-type: none"> ▪ Develop and implement a strategy for enhancing HPC in LTC Homes ▪ Develop strategies to ensure there is adequate access to secondary and tertiary consultation teams in the region's hospitals, hospices, LTC Homes and the community. <p>Supporting Recommendations</p> <ul style="list-style-type: none"> ▪ Implement common validated tools (e.g. decision support tools, pathways and checklists) ▪ Evaluate existing best practices (i.e. symptom management kits) ▪ Identify current best practices and implement evaluate them for common use ▪ Establish a common approach to HPC including the use of common language 	<p>Delivery of high quality, consistent HPC</p> <p>Region wide use of common validated tools</p>
6. Common reporting/data collection and evaluation metrics	No minimum data set and few metrics	<p>Priority Recommendations</p> <ul style="list-style-type: none"> ▪ Establish specific system and provider performance measures for ongoing system planning, monitoring and surveillance to be incorporated into accountability agreements with the Champlain LHIN <p>Supporting Recommendations</p> <ul style="list-style-type: none"> ▪ Establish a standardized minimum data set and list of performance indicators ▪ Assess feasibility of using balanced scorecards ▪ Align with LHIN strategies including data focused on French language indicators 	<p>Minimum data set and common reporting</p> <p>Production of an annual report and 'balanced scorecard'</p>

SUMMARY PLAN			
Key Element	Current State	Recommendations	Future State
7. A strong and well supported primary care service delivery model	<p>Lack of primary care involvement</p> <p>Majority of individuals in the community cared for by specialists</p> <p>Lack of buy-in to primary care model by some service providers</p>	<p>Priority Recommendations</p> <ul style="list-style-type: none"> ▪ Implement a service delivery program with a strong primary care basis supported by secondary and tertiary level palliative care expertise <p>Supporting Recommendations</p> <ul style="list-style-type: none"> ▪ Implement models to providing timely primary care services (including access in LTC Homes) ▪ Build capacity in the system through clinical support, mentoring and education in primary care settings ▪ Strengthen and broaden the current secondary level support to primary care ▪ Link individuals without family physicians to services 	<p>Innovative models to enhance access to primary care</p> <p>Enhanced primary care capacity in the system</p> <p>Enhanced access to secondary and tertiary level support</p> <p>Strategies to assist people who have no family physician</p>
8. HPC service standards and competencies	<p>No regional standards for:</p> <ul style="list-style-type: none"> • service providers • volunteers <p>Lack of monitoring of existing standards</p>	<p>Priority Recommendations:</p> <ul style="list-style-type: none"> ▪ Develop service delivery standards and competencies that will be incorporated into agreements with providers <p>Supporting Recommendations</p> <ul style="list-style-type: none"> ▪ Encourage agencies to be accredited ▪ Identify core competencies for HPC providers at each level (primary, secondary, tertiary) ▪ Monitor achievement of standards 	<p>HPC organizations achieving accreditation status</p> <p>Monitoring of consistency of care across settings</p> <p>Core competencies for service providers</p>

SUMMARY PLAN			
Key Element	Current State	Recommendations	Future State
9. Education, knowledge transfer and research	No standards regarding education	<p>Priority Recommendations:</p> <ul style="list-style-type: none"> ▪ Develop a standardized regional strategy for HPC education for all stakeholders ▪ Expand the use of e-health/tele-health and other technologies to support care delivery and education, particularly in rural and remote regions <p>Supporting Strategies</p> <ul style="list-style-type: none"> ▪ Implement a Regional HPC Educational Program that ensures access to education for all stakeholders ▪ Identify research priorities for the region ▪ Identify methods to translate knowledge into practice ▪ Develop strategies to link with research bodies in Champlain 	<p>Regional, collaborative approach to education</p> <p>Coordination of research priorities</p>

REGULATORY, LEGISLATIVE AND POLICY BARRIERS

There are a number of regulatory, legislative and policy barriers in the health care system that impact on the delivery of HPC. Most of these fall under auspices of the provincial government. In order to move forward and support integration, the Regional HPC Program must identify and develop strategies to address these barriers. Examples include:

- Limitations associated with staffing guidelines in LTC homes that lack the flexibility needed to support dying individuals
- The inability of a body to be transferred from the home without a doctor's signature (nurses can pronounce a death, but are unable to sign a death certificate)
- The funding formula for community support services including community hospice services does not sufficiently recognize the impact of these services and forces agencies to redirect precious resources from direct services to fundraising activities
- CCAC service maximums
- The limited legislated mandate of the LHIN (i.e. the Local Health Integration System Act does not include physician care)
- The CCAC's need to provide professional services as a prerequisite for a client to receive other important services such as an ODP drug card or some home support.

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APPENDIX A HPC PROGRAM DATA

The following information provides a summary of statistical data from individual organizations related to HPC service delivery.

BRUYERE CONTINUING CARE – PALLIATIVE CARE UNIT

- 36 beds
- Based on 2008-2009 statistics:
 - There were 424 admissions
 - Majority of patients had a diagnosis of cancer (92%)
 - 76.2% of patients were between 55 and 84 years of age
 - The majority of admission were from acute care hospital (69%)
 - 87.2% died on the unit (most of the remaining 12.8% return home to die)

BRUYERE CONTINUING CARE – PPSMCS

- Based on 2008-2009 program statistics:
 - 523 patients referred (increase of 97% percent from previous year)
 - 3091 telephone consults (increase of 41.5% from previous year)
 - Total visits 470 (decrease of 13% from previous year)
- * The increase in telephone consults were the result of a directive from the MOHLTC reinforcing the telephone component of the service*

THE OTTAWA HOSPITAL

- Consult team provides HPC services to over 1000 beds across all services
- 2,495 annual referrals to the consultation service
- Based on 2009 statistics:
 - 22,455 visits were made by the palliative consult team
 - 72% of patients had cancer
 - Of the patients seen:
 - 32.5% were discharged home
 - 30% of patients on palliative care service died in hospital
 - 13.6% were discharged to hospice, palliative care unit or another hospital
 - Average LOS on the palliative services was 9.1days
 - Averages length of time from consult being received to patient being seen by a member of the team was <24hrs.
 - 1,494 cancer outpatient visits (cancer and pleurex clinics)

QUEENSWAY CARLETON HOSPITAL

- Consultation services provides HPC to inpatients at the hospital
- Based on 2009 statistics
 - 300 consults
 - Papers complete to discharge is an average of 9 days

CHAMPLAIN CCAC

- Based on 2008-2009 statistics
 - There were 2639 'end of life' care clients
 - Elderly 65%
 - Adults 34%
 - Peds 1%
 - Average LOS 138 days
 - 48% died while on CCAC (in the community)
 - 20% of clients discharged to an acute care hospital
 - 15% died in an acute care hospital <14 days after admission
 - 78% of new referrals originate in acute care hospitals
 - End of life clients:
 - Average LOS on end of life service is 138 days
 - Median LOS is 70 days
 - Mode is 7 days

** EOL care clients are individuals identified through the following question 'would you be surprised if this client died within 6 months?'*

ROGERS HOUSE

- 8 pediatric palliative care beds
- Based on 2008-2009 statistics:
 - 289 admissions
 - Most common diagnosis; cancer, cerebral palsy, as well as genetic, metabolic, neurological and neuromuscular conditions
 - Average LOS was 5.2 days

HOSPICE AT MAY COURT

- 9 residential hospice beds
- Based on 2008-2009 statistics
 - 136 admissions
 - 93% of admissions were individuals with cancer
 - 54% of admissions come from the community
 - 46% of admissions come from acute care hospitals
 - Average LOS is 18 days (down to 12 days in 2009-2010)
 - Approximately 75% of individuals admitted die in hospital
 - 101 patients involved in the day hospice program
 - 32 patients involved in the home support program
 - 119 individuals involved in the family support program
 - 551 volunteers involved with the Hospice

HOSICE RENFREW

- 8 residential hospice beds
- Based on 2009 statistics
 - 66 admissions
 - 88.5% cancer
 - Average age of individual admitted 70 years (range 42-97)

- Average LOS 14 days
- 95% of individuals dies in hospice (may have been in and out of hospice for symptom control, but eventually died in hospice)

CORNWALL HOSPICE

- 10 bed hospice
- 69% of admissions are individuals with cancer
- Average LOS is 21 days

*The Cornwall Hospice has been open less than a year – statistics are based on services since September 2009

FRIENDS OF HOSPICE OTTAWA

- Based on 2009 statistics
 - 91 clients receiving home support
 - 42 clients in the day program
 - 28 clients receive transportation services
 - 53 clients receive phone support
 - 67 clients involved in caregiver support
 - >33 participants in the grief and bereavement program

APPENDIX B
RATIONALE FOR WORKING GROUP ASSIGNMENTS

Working Group	Rationale
HPC Bed Access and Allocation	<ul style="list-style-type: none"> - At the present time, there is no regional plan for the allocation of HPC beds - There are challenges to accessing HPC beds at all levels - There is a need to address the results and recommendations of the Fassbender Report (2006)¹⁶
Services in the Community	<ul style="list-style-type: none"> - Community support services have a significant role in providing HPC services in the community - These services include a wide spectrum of supports including bereavement, caregiver support and volunteer assistance
Rural Models	<ul style="list-style-type: none"> - There is limited access to HPC services including specialists - There are often large distances to travel to bring care to the individual's home - There is a need for enhanced support and education for family physicians and other members of the primary care team - There is an under-utilization of existing consultation services
E-Health	<ul style="list-style-type: none"> - There has been significant advancements in providing care and communication technology in recent years (tele-consulting, outreach education) - Conversely, there has been a low application of technology in the HPC sector - There is a need to implement e-health strategies to better serve rural and remote areas within Champlain - There is a need to explore and implement a HPC database/registry - There is a need to develop a HPC website with information (and possibly short video clips) on available services.
Consultation Services	<ul style="list-style-type: none"> - Different models of consultation services exist in Champlain (rural, urban, hospital and community sectors) - There is a need to maximize reach of consultation services (ensure consultation services are available to adequately support primary care in all sectors)
Patient Flow	<ul style="list-style-type: none"> - There is a need to review 'patient flow' and related processes across HPC settings and services - There is a need to review and standardize criteria for admission to services across settings and services
Primary Care Model	<ul style="list-style-type: none"> - Primary care service providers have the skills and capacity to manage the majority of individuals, yet the current system has high utilization of palliative care specialists for non-complex cases in urban settings - There is a need to increase primary care provider access and utilization of consultation services and supports from experts and

¹⁶ Fassbender, K. (2006) Operational Review and Clinical Audit of the Palliative Care Program at the Sisters of Charity of Ottawa Health Service.

	<p>specialists</p> <ul style="list-style-type: none"> - The primary care service delivery model has the potential to increase system efficiencies in a cost effective manner
<p>Long-Term Care</p>	<ul style="list-style-type: none"> - A significant number of deaths occur in LTC facilities - For the most part, LTC facilities are largely under-resourced - There is a need for increased utilization of HPC consultation services, support and education in LTC - When planning for HPC in LTC settings, there is a need to ensure issues associated with residential care - While improvements have been made, it is believed that there is still a significant number of LTC residents dying in acute care settings

APPENDIX C
PLANNING COUNCIL TERMS OF REFERENCE AND MEMBERSHIP

CHAMPLAIN INTEGRATED HOSPICE PALLIATIVE CARE PLANNING COUNCIL

	Terms of Reference
Mandate	To facilitate, oversee and implement the development of a model for a regional integrated delivery system of hospice palliative care services in Champlain
Date Established	August 2009
Last Revised	August 2009
Report To	The Champlain Hospice Palliative and End of Life Care Network (CHPEOLCN)
Liaison With	The Champlain LHIN
Working Groups	Working Groups will be established to assist the model development process in key areas including: <ul style="list-style-type: none"> • HPC Bed allocation • Community Support Services • HPC in rural settings • Enhancement of primary care capacity • E-health strategies in HPC • HPC consultation services • HPC patient Flow Map • HPC in LTC Settings
Link to Strategic Directions	The model development process will be in keeping with the broad strategic planning directions of the Champlain LHIN and the strategic directions of the CHPEOLCN
Functions and Responsibilities	The functions and responsibilities of the Council include: <ul style="list-style-type: none"> • To provide advice, guidance and strategic oversight to the model development process • To provide support and direction to the members of the Project Office (project team). • To ensure project activities and outcomes are aligned with principles of regional coordination and system integration • To ensure project outcomes address key priorities identified at the Champlain HPC Retreat (April 30th, 2009) • To ensure strong lines of horizontal communication in an effort to avoid duplication • To understand and respect the interest of project stakeholders • To monitor and evaluate the project's progress including adherence to timelines • To provide status reports to the CHPEOLCN • To monitor and ensure effective use of project funds • To receive and consolidate results from Working Groups into one service delivery model • To oversee the community engagement process • To present and recommend a regional integrated model and implementation strategy for HPC, including a leadership component to the CHPEOLCN

Chair	The Chair of the CHPEOLCN will chair the IHPCPC
Terms of Office (Members)	Members will be engaged for the duration of the Project.
Membership	<p>Membership on the IHPCPC will include approximately 7 individuals who meet one or more of the following criteria:</p> <ul style="list-style-type: none"> • An understanding of the HPC service system in Champlain • experience in systems level planning • able to plan from a systems level perspective • ability to influence change • demonstrate organizational objectivity/neutrality • experience in research and/or project evaluation <p>Other organisations / groups / individuals that may have an interest in the development of certain aspects of the model may be invited to join the Steering Committee at any time with the agreement of the members.</p>
Meeting Frequency	The Council will meet initially on a monthly basis, at a time and venue agreeable to the majority of the members. This frequency will be reviewed at a later date at the Chair's discretion.
Project Duration	The Council will function for the duration of the model development process (an estimated 12 months)
Operating Principles	<p><u>Quorum</u> Quorum will be the majority of members.</p> <p><u>Decision Making Process</u> A consensus decision-making model will be used by the Council whereby consensus is defined as the willingness among all members to support a decision once it is made.</p> <p>When consensus cannot be reasonably reached, the Chair, or any member of the committee, can ask for a formal vote. Only those members present will be eligible to vote. If the vote results in a tie, the motion will be considered defeated.</p> <p><u>Conflict of Interest</u> When possible, Council members must inform the Chair prior to or at the beginning of the meeting, if the potential for conflict of interest exists. The responsibility for identifying conflict of interest lies with the Council member with the conflict. The Chair, in consultation with the remaining Council members will decide on how, or if, the member with the conflict will participate.</p>

CHAMPLAIN INTEGRATED HOSPICE PALLIATIVE CARE PLANNING COUNCIL

MEMBERSHIP

José Pereira (co-chair)

Sheila Bauer (co-chair, Sept – Nov 2009)

Jocelyne Contant (co-chair, Nov 2009-present)

Diane Caughey, co-chair, Hospice Palliative Care in Rural Settings Working Group

Greg Doiron, co-chair, Bed Allocation Working Group

Kathy Downer, co-chair, Patient Flow Working Group

Debbie Gravelle, co-chair, Consultation Services Working Group

Cathy Jordan, co-chair, Services in the Community Working Group

Lynn Kachuik, co-chair, Consultation Services Working Group

co-chair, Bed Allocation Working Group

Craig Kuziemsky, E-health Consultant

Janet Morris, Chair, Hospice Palliative Care in LTC Settings Working Group

Glenda Owens, co-chair, Patient Flow Working Group

Frances Renaud, co-chair, Hospice Palliative Care in Rural Settings Working Group

Gerard Yetman, co-chair, Services in the Community Working Group

Project Support Team

Gwen Barton, Coordinator, Champlain Hospice Palliative and End of Life Network

Vivian Thompson, Senior Planner, Champlain LHIN

APPENDIX D

WORKING GROUP RECOMMENDATIONS

Patient Flow Working Group

Mandate: To make recommendations to address issues with transitions and access to services within HPC.

Recommendations

1. There is a need for a more formal ‘system navigator’ role to support individuals, families and service providers. The navigation component would not necessarily be delivered by a specific person, but through a service or team knowledgeable of HPC resources and with the ability to respond to the individual and their family’s needs in a timely manner. At the present time, CCAC has the mandate to be the organization responsible for care coordination. Ultimately, successful navigation/care coordination would result in an enhanced awareness of service options and more seamless transitions for individuals and their families.
2. The ability of service providers to have a more complete understanding of the individual and their family needs would be enhanced by having electronic access to information
3. There is a need to reduce the number of CCAC contracted agencies involved with individuals and their families. In addition to challenges related to continuity of care, the number of potential service providers makes it challenging for agencies to build the required level of HPC specialty and expertise.
4. There is a need for individuals and their families to have simplified access to information on HPC and related services (i.e. through Champlain Healthline or other website)
5. There is a need for decision support tools to assist in identifying options and making decisions around the individual’s location for end of life care (accommodating individual and family wishes as much as possible)
6. A transition checklist to ensure service providers are aware of the pieces that need to be in place to support the transition process (i.e. what medications the individual is on and if they are available in the new setting what equipment/treatment individuals require and if health care providers have the skill set to manage)
7. There needs to be an adequate number of palliative care beds in the system to meet the needs of individuals and their families (residential hospice, acute palliative care, chronic palliative, respite and tertiary level of care).
8. The system needs to continue to support the existing primary care service base and continue to build on this as the foundational component for HPC
9. There is a need to establish and support palliative care ‘hubs’, particularly in rural areas, where individuals and their families can access information on resources.
10. The philosophy of HPC and the HPC approach needs to be introduced to individuals and their families early in the disease process.

Services in the Community Working Group

Mandate: To make recommendations regarding the availability, access and utilization of community support services in HPC.

Recommendations

Individual & Family/Informal Supports

1. There is a need to establish a comprehensive list of available services in the community for individuals with HPC needs and their families. There is a need to take advantage of sharing awareness of resources through knowledge transfer opportunities such as the Wellspring Ottawa program (being developed in conjunction with the Ottawa Cancer Centre) or the GEM Program (linking older individuals visiting the emergency room with day hospice programs to address the need for socialization and caregiver respite).

People in the community need access to right service, with the right level of support at right time. It is essential that services in the community be provided in a way that enhances the strengths and supports already in place for the individual and their family.

HPC Services in the Community

1. HPC service delivery agencies need to ensure there is a focus on the caregiver (not just individual). Caregivers are very much part of the individual's journey and are critical to enabling individuals to stay at home as long as possible. Care for the caregiver is essential to maintain caregiver health and independence.
2. Agencies providing HPC should be accredited by a recognized body
3. The CCAC, as the agency responsible for coordinating publicly funded home care services, needs to ensure processes are in place to ensure members of the inter-professional health care team have the knowledge and skills to provide quality palliative care in the community. This includes a monitoring component to ensure consistency of care delivered.
4. The Working Group recommends that CCAC undertake a review as to 'when' an individual is identified as "palliative". This designation is often associated with a significant increase in available resources, but it is often done too late in the disease trajectory. Earlier access to some specialized HPC services would make a significant impact on the lives of the individual and their family members.
5. There is a need to explore options and funding for spiritual care including bereavement support as an important component of HPC services.¹⁷

Other Services in the Community

1. There is a need to establish stronger linkages with formal HPC services and ensure information on available services is shared with individuals and their families earlier in the disease process.

¹⁷ Professional Hospice Palliative Care Spiritual Care Provider, Profile of Major Areas of Responsibility and Related Tasks (2005), The Pallium Project (Phase II) www.pallium.ca

2. Community Support agencies provide a wide range of services to individuals in their homes. To date, there hasn't been a specific focus on how to meet the needs of the individuals. The Working Group recommends that a connection be made with the Community Support Services Coalition to identify strategies to improve access to their services by individuals and their families. The CSS sector has been providing services to individuals with HPC needs including those with chronic illness as part of the routine services offered to all individuals. There has not been a formal consideration regarding how to provide these services in the context of HPC. This would require a shift in resources and education of staff, volunteers and others involved in these services. In addition, the fee for service model for CSS may create a barrier for individuals accessing these services and needs to be considered.
3. Access to palliative care services in Retirement Homes is increasingly becoming an important issue. At the present time, there are no standards in place, however, some retirement homes are advertising their capacity to provide HPC to their residents. It is recommended that the regional plan for HPC include a strategy to link with local ORCA¹⁸ representatives to create the standards, training and service support required to enhance these services. In addition, this planning should include clear expectations and understanding regarding how other supports in the community provide services in these settings and set guidelines for engaging these on a timely basis.
4. In order to enhance the capacity of primary health care practices, it is essential that other professionals in the practice also understand the needs of HPC clients and the range of service options in the community. One initial strategy to begin to build this capacity may be through the local RNAO Family Practice Nurses Interest Group.
5. The work group acknowledged that there may be other service providers who provide service to this client group, especially as it applies to individuals who enter this system as part of the aging process (e.g. RGAP). Strategies need to ensure that these providers have a good understanding of HPC and how to connect their individuals appropriately. One such opportunity exists through the development of the GEM nurse role.
6. It is recognized that the needs of children require additional specialized services. Additional investigation needs to be conducted to identify service needs for Champlain's pediatric population. Efforts will also need to be made to address the needs of other client groups such as individuals who are developmentally delayed and other marginalized populations.

¹⁸ Ontario Retirement Communities Association

Consultation Services Working Group

Mandate: To make recommendations regarding models and functions of PC consultation services across the Champlain LHIN.

Recommendations

1. Prior to implementation of any model there is in depth consultation/engagement with primary care and other stakeholders to ensure that we are meeting the needs.
2. The models of consultation for the Champlain region need to be flexible to meet the needs of the individual and their family as well as the needs of the primary care providers. There is a need to support primary care providers by recognizing there are different levels of involvement depending on their skills and availability.
3. Education and mentoring are important tools to increase the capacity of the system to provide HPC. Service providers providing consultation services should ensure that every contact with individuals, families and service providers is used as an opportunity to educate (teaching in the moment) to facilitate knowledge transfer and remain actively involved in educating health care providers in other venues.
4. Palliative care consultation teams must be inter-professional .
5. Members of a consultation team must have received specialized education in Palliative Care and have demonstrated Palliative Care competencies. Where certification in HPC is available in a specialty it should be achieved – i.e. CNA certification, palliative care fellowship, palliative care volunteer certification. In some cases, equivalent experience can be substituted for specialised education as in the case where a health care provider has been actively practicing in the field of Palliative Care for many years and has demonstrated achievement of specific palliative care competencies but has not completed a formal fellowship or speciality training program.
6. Members of a palliative care consultation team possess clinical expertise in Palliative Care assessment, interventions and evaluation in the following areas:
 - a. Pain and symptom management
 - b. Psychosocial, spiritual care
 - c. End of life care
 - d. Communication
 - e. Transitions
7. Members of a palliative care consultation team demonstrate the following types of leadership:
 - a. System leadership
 - ability to institute change
 - ability to allocate resources
 - comprehension of the team’s impact / fit within the regional system

Consultation Services Working Group

Mandate: To make recommendations regarding models and functions of PC consultation services across the Champlain LHIN.

b . Local leadership

- Ability to educate, coach and mentor other health care professionals to disseminate knowledge about Palliative Care interventions.
- Have access to and apply the latest research, evidence informed guidelines and best practice information to improve quality of service and, where possible, participate in and generate research
- Ensure accurate and appropriate assessment by using validated tools when appropriate.

8. Palliative care consultation teams must evaluate services and outcomes by maintaining data regarding consultations

9. Secondary palliative care consultation services must be located as close to home as possible. Secondary consultation services must have 24/7 access to tertiary level services.

10. The formation of cross-service consultation teams needs to be explored. Individualized teams would be created to meet the needs of individuals and families. This would involve identifying all consultation services and individuals with the skill set to provide consultation and developing a central referral site or formalized 'hub' which would be able to assist primary care service providers in accessing consultation services. These teams would not necessarily be housed in one geographical area or be paid from one institution / service budget. This 'hub' would also provide access to patient information to facilitate the information sharing process.

Implementation efforts would need to work closely with other providers such as FHT's or residential hospices as 'spokes' or smaller hubs that currently exist in the system.

11. Formal (i.e. annual meetings, retreats) and informal team building opportunities need to be created to foster relationship building among consultation team members and continue to support the cross-institutional concept of a regional consultation team approach.

12. In order to move forward on the regional approach to consultant services, a formal agreement (i.e. MOU) would need to be developed to demonstrate a commitment to this initiative.

Hospice Palliative Care in Rural Settings Working Group

Mandate: To make recommendations regarding a model(s) for the delivery of HPC services in rural settings

Recommendations

Support in the Home

1. Continue to support and implement symptom management kits as part of the EOL care to assist community based interventions and as a practice that assists in reducing number of unnecessary visits to hospitals
2. Continue to encourage the use of the Chart in the Home and update the current model based on feedback from the community.

Bereavement

3. Establish mechanisms to enhance availability and utilization of bereavement services

Transition Between Settings

4. Introduce mechanisms that support transition planning such as discharge checklists and enhanced communication strategies

E-Health Opportunities

5. Investigate e-health opportunities to facilitate access to palliative care experts in rural and remote regions (i.e. similar to the technology used in the heart institute to assist with distance assessments) and to support per networking and educational opportunities for health service providers.
6. Develop systems to support electronic access to health records to promote information sharing and inter-professional collaboration

Funding Models

7. Investigate hospice programming funding models that rely on fundraised dollars in communities where the ability for services to fundraise are extremely limited.
8. Implement strategies that recognize the human resource and funding implications of providing services in settings which require significant travelling between care delivery settings and individuals homes.

Standards

9. Develop/adopt standards for screening, selection and monitoring of HPC service providers and volunteers
10. Identify core competencies for HPC health service providers.
11. Continue to promote the standardization of tools and equipment used regionally.

Hospice Palliative Care in Rural Settings Working Group

Mandate: To make recommendations regarding a model(s) for the delivery of HPC services in rural settings

Increase Capacity of Service Providers

12. Enhance formal and informal educational opportunities for HPC service providers in rural communities (i.e. peer networking, mentoring).
13. Continue to support the rural based PPSMCS palliative care nurse consultant in Renfrew and Eastern Counties
14. Conduct rounds in all settings where HPC is provided to promote a holistic approach to care, inter-professional collaboration and relationship building

French Language Services

15. Ensure the needs of French language individuals and their families in Champlain are met.

Leadership

16. Promote a regional leadership structure that allows for local area input and decision-making capacity
17. Explore the concept of establishing HPC 'hubs' in rural settings associated with hospice programs (where available) to serve as a principal base providing centralized information and support to individuals, families and health care providers.

Hospice Palliative Care in Long-Term Care Settings

Mandate: To make recommendations with respect to the delivery of HPC in long-term care settings.

Recommendations

Adequately Resourced

1. LTC homes do not have the same staffing models as found in an acute care hospital or specialized HPC unit. They are staffed for the stable LTC resident, not one in need of palliative care. It is important to note that despite an increasing acuity and complexity of LTC residents, staffing ratios have not changed.
2. There is a need to expand the High Intensity Needs funding model to support additional resources for residents who require end of life care, including additional staffing resources to focus on the dying resident without reducing the care available to the other residents in the Home and the necessary supplies and equipment to provide adequate comfort care.
3. There is a need to establish equity and flexibility into the LTC system in order that there is a sufficient level of care available to support actively dying residents.
4. Access to equipment and supplies that contribute to the comfort level of residents and families and quality palliative care such as special mattresses and bed-chairs for family members need to be made available.
5. Palliative residents in LTC homes need to have access to key members of the inter-professional palliative care team (i.e. social workers, spiritual workers), to provide psychosocial support to the resident and their families.

Care Pathways

6. Tools, such as care pathways, that describe signs and symptoms within the illness trajectories, including end of life, for some of the more common non-malignant illnesses where palliative care can positively impact the dying process need to be explored/developed and adopted for use in LTC homes.

Access to Expert HPC Services

7. Health service providers in LTC homes need to be aware of available community consultation services to address questions and concerns regarding HCP service delivery.
8. There is a need to explore options such as the Geriatric Emergency Management model, Nurse Practitioner outreach and on-site Nurse Practitioner to strengthen relationships with acute care hospitals.
9. The model used by the Psychogeriatric Outreach Team is a recommended approach to support HPC and to increase the LTC Homes knowledge and awareness of HPC. This model facilitates a relationship between staff in the Home and the consultation service by having a regularly scheduled consultation visit in each Home. Education and mentoring opportunities are intrinsic to the regular visits, along with resident case review and management.

Hospice Palliative Care in Long-Term Care Settings

Mandate: To make recommendations with respect to the delivery of HPC in long-term care settings.

Access to Primary Care

10. The on-site availability of a nurse practitioner in LTC homes needs to be explored in order to address key issues such as the shortage of physicians and the increasingly complex needs of LTC residents and to provide much needed support to care staff.

Education

11. Simplify access to educational opportunities for LTC staff (e.g. increasing awareness of opportunities and providing staffing coverage to enable them to attend available courses) need to be implemented (building on the core components developed through the MOHLTC Initiative #1 funding)

12. Ensure education of LTC staff in the area of HPC encompasses spiritual and bereavement components to address the holistic needs of the resident and family.

13. A list of available HPC resources that could assist LTC home staff in providing HPC would be a useful tool and needs to be developed.

14. There is a need for education of acute care hospital staff that in most instances, it is appropriate for LTC residents to visit the emergency room.

Bed Allocation Working Group

Mandate: To make recommendations re: the availability and distribution of all levels of HPC beds in Champlain.

Recommendations

1. Work with Konrad Fassbender and his group to conduct a LHIN wide study that will help to determine the total number and types of palliative care beds required across the Champlain LHIN
2. Bed allocation decisions consider the concept of critical mass such that sufficient beds are grouped together to provide both economies of scale and to facilitate hiring and educating of palliative care staff.
3. Palliative care beds are located according to intensity and level of care provided.
4. Staffing for palliative care beds is designated according intensity and level of individuals' needs.
5. Palliative Care beds are staffed by inter-professional teams who receive specific education and ongoing professional development in assessing and managing palliative care individual and family needs.
6. Palliative care beds may be located in various levels of facilities including academic tertiary care hospitals, acute care hospitals, community hospitals, chronic continuing care hospitals, long term care settings and free standing hospices.
7. Consideration should be given to locating newly created hospice beds in pre-existing settings of care to achieve cost effectiveness.
8. Planning for new Palliative Care beds should be vetted and approved by an oversight governing body that is part of a Regional Palliative Care Program to ensure fit with the Regional Program vision and needs.
9. All palliative care beds in the Champlain LHIN should seek Accreditation Canada status for Palliative Care.
10. Collaboration must occur across sectors to ensure appropriate planning, access to the right level of care and care in the correct setting for individuals in the Champlain LHIN.

Primary Care Focus Group Session

Purpose: To investigate what do we need to do we increase the involvement of primary care practitioners and engage physicians in the delivery of hospice palliative care

Key Points

- Build strong relationships with skilled agency staff providing care in the individual’s home to create an element of trust between the physician and the nurse. The ability of community nurses to conduct quality assessments and relay this information to physicians creates a level of predictability and pre-emptive problem solving related to care needs, limits the need for home visits by the physician, and ultimately, limits unnecessary visits to the emergency department.
- Address the concerns regarding the number of agencies involved in the delivery of palliative care services in the community. This affects the continuity of care, concentration of expertise and the ability to establish relationships between primary care physicians and the nurse in the individual’s home.
- Ensure family physicians are aware of the supports that are in place to assist with their involvement in HPC. In particular, the availability of consultation services through PPSMCS or community based palliative care physicians as well as local champions with extensive experience in providing HPC.
- Explore strategies to address the issue of on-call and after-hours coverage. This might include the establishment of teams that ensure reliable, geographically co-located call groups where physicians share the responsibility for call and have centralized access to patient information as required. This would require a critical mass of physicians per group to ensure the frequency of being on call is limited. One limitation to this approach is that individuals registered with a specific FHT or FHG are not able to access services of another FHT or FHG. This would result in a financial penalty to both groups.

THAS (Telephone Health Advisory Service) was another identified option to assist with the issue of on-call coverage.

Strategies to address on-call issues need to also consider financial remuneration; in some cases, family physicians may not be aware of existing OHIP payment possibilities..

- Simplify the current complexities in the system by clearly articulating processes to assist with system navigation. This would assist primary care providers in identifying and accessing support for their patients.
- Ensure CCAC case managers and agency staff recognize the importance of the primary care model and support the involvement of family physicians whenever possible
- Explore the possibility of family physicians being able to register with Healthcare Connect when their practice is open to new palliative clients. Currently, there are no parameters where doctors can identify a specific type of individual they are able to accept. If physicians could specify their practice was open to individuals requiring palliative care, it may decrease the number of ‘orphan patients’.

Primary Care Focus Group Session

Purpose: To investigate what do we need to do we increase the involvement of primary care practitioners and engage physicians in the delivery of hospice palliative care

- Explore the concept of ‘shared care’, recognizing the risk that this may create a dependency on specialist service providers.

How do we engage family physicians?

- It is often difficult to engage family physicians as they are a fairly independent group of health service providers. However, family physicians are increasingly becoming more involved in group practices (Family Health Teams, Family Health Groups, Family Health Network and Family Health Organization). This re-organization of primary care services is expected to enhance communication among physicians and hopefully, begin to address important issues related to HPC delivery such as on-call and after-hour coverage.
- The local branches of the Academy of Medicine were also identified as organizations that could assist in enhancing communication with family physicians.
- It was suggested that for planning purposes we attempt to identify the number of physicians currently involved in HPC. This could be achieved by accessing OHIP information related to billing codes specific to HPC (i.e. K023, B996, B998). Using postal codes, we may be able to map the geographical location of those physicians.
- It was also suggested that we attempt to identify the number of people in Champlain (by sub-regions) who currently do not have a family physician.

APPENDIX E

INTEGRATED MODEL FOR HOSPICE PALLIATIVE CARE STAKEHOLDER ENGAGEMENT PLAN

BACKGROUND

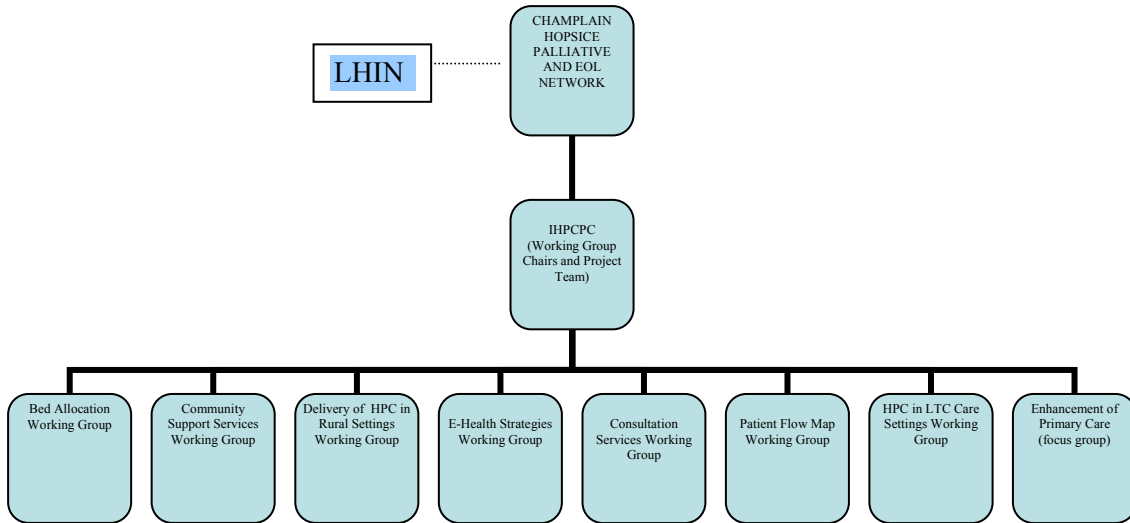
The Champlain Hospice Palliative and End of Life Care Network (CHPEOLCN) is a collaborative of individuals representing different sectors and services of hospice palliative care in the Champlain region. The purpose of the Network is to develop a shared vision and provide integrated, collaborative leadership in support of strategic directions for hospice palliative care.

Early in 2009, the Network was approached by the Champlain Local Health Integration Network (LHIN) and given the mandate to develop a comprehensive, integrated palliative care service delivery model and implementation plan. The main objective of this initiative is to ensure a patient and family focused service delivery system where HPC recipients of care have access to coordinated, accessible and accountable palliative care services in the Champlain District. Ultimately, it is envisioned that this regional approach to service delivery will translate into increased deaths of HPC patients in the community (home, hospice and long-term care facilities), and conversely, a reduction of deaths of patients in acute medical and surgical units, a decrease in the number of inappropriate admissions to emergency room services and a more coordinated and efficient use of existing resources.

The Network recognized the importance of community engagement and has participated in a number of related activities over the years that support this principle including contributing to the LHIN's primary care sector planning and presenting at the Palliative Care Rounds in 2008. More recently, HPC service providers and other individuals interested in the delivery of HPC participated in a retreat (April 2009) to discuss the concept of a regional model and obtain consensus regarding priority areas for system re-design. More than 60 stakeholders from across the Champlain Region attended the session and participated in the dialogue with the majority extending their support for the Network to undertake a model development process.

PROJECT PLANNING STRUCTURE

To move the Project forward, the Network has established 7 time-limited working groups to address the priority areas of system re-design identified at the Retreat. A separate focus group will be held to identify strategies to support and engage primary care service providers in the delivery of HPC in Champlain. The Chairs of each working group have come together to form the Integrated Hospice Palliative Care Planning Council to oversee and guide the development and implementation of the model. The Planning Council will report to the Network, but will also be responsible for ensuring a service model and a suggested implementation strategy is able to be presented to the LHIN Board in April 2010. A schematic depicting the planning structure can be found below.



COMMUNITY ENGAGEMENT FOR THE INTEGRATED HPC MODEL DEVELOPMENT PROJECT

Community Engagement is about encouraging and supporting local people to participate and be involved in decisions about local services. Community engagement is a primary objective of the Champlain LHIN (and a legal requirement as defined in the *Local health System Integration Act 2006*) and an integral component of the HPC model development process. This level of open and ongoing communication is a key ingredient to achieving the following goals:

- Enhancing local accountability
- Promoting a shared sense of understanding and responsibility for health system utilizations and opportunities for improvements
- Making decisions more focused on the needs of people impacted by it
- Providing more opportunities for community partners to have meaningful input into the decisions that impact them
- Working towards locally sustainable solutions as appropriate to each community.

The purpose of this document is to provide an overview of the key steps and milestones related to the model development process and a recommended approach to community engagement. These are described in the attached workplan. Once a model has been developed and endorsed by the LHIN, the component of the engagement strategy related to model implementation will need to be revisited as it may be influenced by recommendations put forward as part of the model.

**COMMUNITY ENGAGEMENT/COMMUNICATIONS STRATEGY
WORKPLAN
SEPTEMBER 2009 – JANUARY 2010**

<i>Project Activities</i>	<i>Communication/Engagement Objective</i>	<i>Target Audience</i>	<i>Communication Techniques</i>	<i>Action Required</i>
1. Palliative Care Retreat	<p>To seek input from key stakeholders re: issues in the palliative care service system</p> <p>To obtain consensus re: priority areas that need to be addressed</p>	<p>All stakeholders in Champlain that may be impacted by any palliative care related planning initiatives:</p> <ul style="list-style-type: none"> – Specialized Palliative Care Services – Hospitals (Acute and chronic) – LTC facilities – Retirement Homes – Community Health Centres – Community Support Services – Volunteer Sector – Educators – Cancer and Non-Cancer Associations – Family Physicians – Family Health Teams 	<p>One-day facilitated retreat</p> <p>Report on the outcomes of the day circulated to participants</p>	Completed in April 2009
2. Establishment of Planning Council and Working Groups	<p>To inform key stakeholders about the initiation of the Project</p> <p>To encourage involvement of stakeholders in the planning process</p>	<ul style="list-style-type: none"> – All stakeholders (listed above) 	<p>Communiqué highlighting:</p> <ul style="list-style-type: none"> – Overview of Network and Planning Council – Project goals and objectives 	<p>Draft and distribute communiqué (early Oct. 2009)</p> <p>Establish Project Website as a component of CCAC's Healthline (end</p>

	To foster transparency of the planning initiative.		<ul style="list-style-type: none"> – Project leaders/chairs – Website availability <p>Establishment of a Project website for communication purposes</p> <p>Request participation of stakeholders in the planning process</p>	<p>Oct. 2009)</p> <p>Invited representatives of HPC community to participate on Working Groups (completed)</p>
3. Working Group activities and efforts to achieve objectives	<p>To inform and seek community input into specific planning activities</p> <p>To foster champions in the community for ongoing planning and model implementation</p>	<p>Key stakeholders within each specific working group sector:</p> <ul style="list-style-type: none"> – LTC/Res Homes – Rural HPC Providers – Community support services – Consultation teams – Hospitals and hospices with /or planning for palliative care beds – E-health? 	<p>Email sharing of working group reports to key stakeholders</p> <p><i>Any targeted consultation required by a working group must be approved by the Planning Council to ensure a coordinated approach.</i></p> <p>Post reports on website</p>	<p>Working Groups to develop list of key stakeholders (mid Oct. 2009)</p> <p>Reports distributed by email and posted on website.</p>
4. Consolidation of Working Group outcomes into a Regional Model for HPC in Champlain	<p>To seek stakeholder input into the proposed service delivery model for HPC in Champlain</p> <p>To ensure proposed model is reflective of the existing and future need in the community.</p>	All stakeholders (listed above) including family/patient representatives	Community consultation process	Community meetings will be held in December (to share and seek feedback on project objectives and initial direction) and February (to share and seek feedback on the regional model for palliative care) in each of the three geographical

				<p>regions of Champlain (Eastern Counties, Ottawa and Renfrew County).</p> <p>Seek assistance of Community Care Advisory Forums (CCAF's) to engage community participation.</p> <p>Incorporate community consultation results into regional model</p>
5. Present final model to LHIN Board (April 2010)				Presentation to LHIN (May 2010)
5. Model implementation	To continue to provide information to and seek input from stakeholders on implementation process	All stakeholders		Will need to be revisited once a model has been developed

APPENDIX F

STAKEHOLDER ENGAGEMENT FEEDBACK SUMMARY

1. INTRODUCTION

In April 2009, the Champlain Hospice Palliative and End of Life Care Network was given the mandate from the LHIN to develop a regional plan for a more integrated and coordinated approach to the delivery of hospice palliative care (HPC) services. Following an in-depth planning process involving numerous working groups with representation from across the Champlain region, the draft document entitled “Regional Hospice Palliative Care Program for the Champlain LHIN” was developed. The Plan, which is founded on the primary care service delivery model and the Canadian Hospice Palliative Care Association’s ‘Model to Guide Hospice Palliative Care’, describes the establishment of a Regional HPC Program as a forum to oversee and implement a number of foundational and supporting recommendations designed to improve HPC in Champlain.

In order to provide an opportunity for organizations and individuals interested in HPC to share their views of the draft Plan, a stakeholder engagement process was conducted. Information received through this process will serve to enhance the current plan and ensure the development of a system that meets the needs of the residents of Champlain.

2. STAKEHOLDER ENGAGEMENT PROCESS

During the month of April 2010, 20 facilitated meetings were held involving approximately 350 service providers and 55 individuals with HPC needs, their families and program volunteers to solicit feedback on the draft Regional HPC Program Plan. In an attempt to reach a broader audience, community members were invited to provide feedback via a SurveyMonkey questionnaire.

The document and link to SurveyMonkey were widely distributed by email with a request to circulate the information to anyone they feel would be interested in commenting on the plan. A total of 37 (34 English and 5 French) completed surveys were received through this means. A translated version of the document and questionnaire were also made available.

A list of facilitated sessions held and organizations/groups that received targeted invitations to respond using SurveyMoney is attached.¹⁹

The information received through the stakeholder engagement process is highlighted in this section of the report. An initial response as to how each issue will be addressed is also presented. This summary does not provide an exhaustive list of points raised during the discussions and interviews, but presents common issues and recurring themes that surfaced during the conversations and through written feedback.

¹⁹ Using a likert scale, SurveyMonkey respondents were asked to rate their level of support for the key elements, recommendations and the overall Regional HPC Program Plan.. These results are found in Attachment 2.

Please note that specific comments related to wording suggestions and clarification on terminology were captured and addressed, but have not been presented within a specific 'theme' in this report.

3. FEEDBACK FROM CLIENTS, CAREGIVERS AND VOLUNTEERS

With the assistance of Friends of Hospice and Hospice at May Court, 4 facilitated sessions were held with clients and volunteers within the day programs at these two organizations. A total of 54 clients²⁰ and 28 day program volunteers participated in these discussions. Input from a few caregivers who participated in other engagement sessions also contributed to this feedback.

Much of the conversation with clients focused on their personal experiences with the system and less on the proposed direction of the draft Regional HPC Program Plan. Volunteers also spoke to personal experiences as well as their observations working with individuals participating in the program. The themes of these conversations, summarized below, speak strongly to the need for enhanced integration and coordination of HPC services and more dedicated focus on the needs of caregivers. Actual quotes from participants have been used to further demonstrate these findings .

General Comments

"I am pleased to see something being done to change the current system and I am glad to be consulted"

" This plan makes a lot of sense and is long overdue – Unfortunately we won't see the changes in our lifetime"

"I am angry this has taken so long"

Comments received related to the Regional HPC Program Plan supported the direction, but wished it had come sooner so they could have benefited from a more coordinated and integrated service system. Participants recommended that we explore models of integration that are working well, including the Falls Prevention Program and models of transition with the children's services sector.

a. Access to Information and Services

"Need to be able to access services outside of 9-4"

"The 1st step is info to get control of your life back. Without information, there is no 'patient-centred care'."

"Looking back, I could have used a lot more help with Child care, cooking help, housework help, etc. but no funding for that. My husband could not help as he works full time. We were not eligible for assistance."

²⁰ This number includes 53 individuals living with life threatening illness and 1 family member.

What We Heard

Participants highlighted the need for additional support to ensure future clients of HPC services have access to information on the services that are available to them. The concept of a 24-hour information line, or ‘one-stop-shopping’ for information rather than depending on a service provider to ‘have all the answers’ was identified as a service that would have helped them on their journey.

In Response

The need for enhanced access to information, not only for individuals and their families, but for service providers and volunteers is an important component of the proposed Regional HPC Plan. Strategies include working to put into place a well-coordinated information system, in partnership with organizations that have the mandate to provide information including such as the CCAC, 211 Ottawa and others that have established some components of the required system.

b. Service Integration and Coordination

“There is a lack of communication from one staff person to another and no follow-up so things don’t get resolved. Patients don’t know who to talk to make it work better.”

“There needs to be someone in the centre responsible for coordinating services. Too many people providing home care in silos - Need someone to mediate.”

“There is a lack of understanding of community services by health professionals – scattered knowledge. Information sharing depends on how efficient & interested health professionals are.”

What We Heard

Clients clearly experience challenges with respect to communication among services and when transitioning within the system. There must be options for the system to assume responsibility for “care” coordination when required and to support clients and families in their efforts to navigate the system.

In Response

The underlying premise of the Regional HPC Program plan is to address issues that will enhance integration and coordination of services and the larger health system. Fundamentally efforts must be aimed at improving the experience of individuals and their families throughout their journey.

c. Assistance with System Navigation/Advocacy

“When I was asked by a nurse if I wanted to see a Social Worker, I didn’t know why I would want to see one. I didn’t have information about what they did.”

“Are family members being told what they have a right to? Are they being encouraged to ask?”

“Unless you are naturally assertive, you get lost in the system.”
“There is not nearly enough emphasis on “consumer” input!”

What We Heard

Participants were clear that access is not only about having information available, it is also about knowing *what* to ask and having knowledge about how the system works. The assistance of someone knowledgeable about the system and services to assist system navigation is an important component to ensuring individuals have access to the resources they need, in a timely manner.

In Response

The issue of system navigation is acknowledged as a priority recommendation in the Regional Program Plan

d. Understanding of the HPC Approach

“Since I’ve been coming to Hospice at May Court – people ask why I’m going as I’m not dying.”
“Is hospice for all diseases – or only cancer?”

What We Heard

There is a need for education and explanation regarding what is ‘palliative care’ and that it is much more than end of life. Palliative care actually is a philosophy of care for living, surviving, fighting the illness. There is a big need for education in many forms, recognizing cultural differences, varying literacy levels and that many older individuals do not have access to computers.

In Response

The need for education and increasing awareness for all stakeholders including the general public about the continuum of hospice palliative care services and the concept of the ‘palliative care approach’ will be a priority for the new Regional HPC Program.

e. Need for pastoral care

“Need pastoral care – a big missing chunk. Many issues in palliative care not dealt with by anyone.”
“Early on, there needs to be someone on the team with a counseling background to assess psycho-social needs.”

What We Heard

A number of participants identified that shortage, and in some situations, absence of spiritual care support to help individuals deal with these important issues, in a culturally sensitive manner.

In Response

The Regional HPC Plan recognizes the importance of the involvement of an inter-professional team as part of a holistic approach to service delivery. The team includes spiritual care workers.

f. Opportunity to Remain Home as a Realistic Choice

"It is financially cheaper to keep me at home"

"I hear horror stories from LTC and am afraid to go there"

What We Heard

For the most part, individuals with life-threatening illness want to remain in their own home for as long as possible. Participation in day programs such as those offered by the Hospice at May Court and Friends of Hospice introduce people to end of life options that are available in the system, thereby reducing anxieties of the unknown.

In Response

Although one of the objectives of HPC is to support the individual in dying in their location of choice, there are situations where, due to extensive care requirements and/or changes in the individual's wishes, a HPC bed, in a residential hospice or other facility, is required. A priority recommendation of the Plan is to work with providers to ensure, regardless of where an individual is in the system, that they have access to the same standards of care and competencies that are evidence-based and build on best-practices. The intention is to develop a community-based, client and family focused hospice palliative care system.

4. FEEDBACK FROM SERVICE PROVIDERS

General Comments

Throughout the consultation process, there was general support with the direction described in the Regional HPC Program Plan. There was recognition for the need to address the current challenges in the system with respect to the lack of service coordination and the need for integrating mechanisms to ensure individuals and their family members have access to the range of services they require in a timely manner delivered by competent service providers. At the same time, there was a strong message to ensure that aspects of the system that are working well, be sustained.

It was noted that the document presented a fairly high level plan. Stakeholders identified the need for ongoing consultation as additional details are fleshed out and operational decisions are made. Some have said that "what has been lacking is strong leadership and good governance with funding authority as well as a truly inclusive process that does not just favour the large institutional models"

a. Client-Centred, Community Based Model of Service Delivery

What We Heard

Although one of the key planning principles identified in the document spoke to the ‘importance of a holistic person and family-centred approach to care’, this was not always evident within the document. It needs to be clarified that the Regional HPC Program is being established to improve the integration and coordination of services that will thereby, result in a better health care experience for the individual and their family members/caregivers. This would include the delivery of services as close to the individual’s home as possible with the goal of enabling the individual to remain at home a long as possible.

Some people express concern that the Leadership Committee’s membership as “currently laid out, risks development of HPC services too heavily weighted on tertiary care”; the suggestion is that the Committee “needs to be balanced with direct stakeholder representation such as experienced informal caregivers”.

In Response

The Key Elements which form the foundation for the recommendations in the report will be framed from the patient and family member/caregiver perspective to demonstrate the impact their implementation will have on individuals who receive services.

The concept of seamless care and service delivery through community ‘hubs’ will be promoted to support the planning principle that states ‘decentralize where possible and centralize when necessary’.

b. Maintain What is Working Well

What We Heard

While it was generally supported that a more integrated and coordinated approach would ultimately benefit the individual and their family, there was also recognition that there are positive aspects of service delivery in the current system that are functioning well with the involvement of skilled health care providers, committed family members/informal caregivers and volunteers. It is important to identify and build on these process and relationship successes. This is of particular concern where providers have worked collaboratively and over time, have developed unique and creative strategies to ensure their clients have access to the services they need.

In Response

Ongoing stakeholder engagement and consultation as well as system wide evaluation will assist in identifying best practices and aspects of service that need to be supported and sustained.

c. Simplify and Streamline Requirements of Providers

What We Heard

The concept of a Regional HPC Program was well received, but with some cautionary advice. A Regional Program is seen as an important component to facilitate integration, but there is a real risk of creating another layer of bureaucracy in an increasingly regulated health care system. Health care organizations report being already overburdened and struggling with lengthy and detailed reporting requirements. For some organizations, HPC is only a small component of the service they provide. The capacity of smaller organizations to collect and report on data must be taken into consideration when identifying metrics requirements.

The concerns about system capacity to address multiple indicators have frequently been raised. People have also advised caution about too much emphasis on important factors of good care that are difficult to measure and therefore “ignored”.

We are also reminded that success is likely more related to genuine collaboration than to “formal” agreements.

In Response

The Leadership Council that will be established to oversee the Program will work closely with health service providers and the LHIN to ensure a streamlined and reasonable approach to data collection and reporting.

The formal agreements are not intended to be “service agreements” with providers but a means of recognizing the commitment to HPC standards and agreed-to practices, for example.

d. Supporting the Primary Care Service Delivery Model

What We Heard

The majority of stakeholders acknowledged the importance of the primary care service delivery in creating a sustainable HPC system. However, concern has been expressed regarding the realities of the current situation – particularly with respect to the over dependence on the specialist care model, the inconsistent involvement of family physicians as part of the care team and the number of individuals who do not have a family physician.

Some have noted that the Regional HPC Program should specify that “primary care providers” may include professionals other than physicians such as Nurse Practitioners, Pharmacists for example.

In Response

The Regional HPC Program Plan emphasizes the need to develop strategies to support primary care providers involvement in providing HPC. Strategies will focus on enhancing education, enhancing access to consultative support and addressing system barriers that impact on primary care providers ability/willingness to provide HPC.

e. Comprehensive System Planning

What We Heard

There is a need to ensure the continuum of HPC services and service providers is taken into consideration as part of the Program. Some examples of specific comments received include the following:

- There is a need to ensure the Regional HPC Program has a balanced perspective related to service provision to individuals who present with cancer and non-cancer diagnosis. The perception to date is that there has been a significant focus on the delivery of HPC to individuals with cancer despite the growing needs related to the increasing incidence of chronic disease in our society.
- A strategy needs to be developed to involve the gamut of providers in the planning and implementation of the new regional program. This is more challenging for some groups such as family physicians and service provider agencies who are very involved in HPC delivery, but do not have service provider agreements with the LHIN and who may or may not have limited structures for communication with their colleagues.
- Community support services have an important role and contribute significantly to the ability of the individual to remain in their home as long as possible. Organizations providing these services need to consistently be recognized as a HPC service delivery partner.
- The Regional HPC Program needs to recognize the invaluable contribution of the informal caregiver and volunteers and ensure support is available to provide them with the assistance they need to care for their family member including respite care.
- The community repeatedly points out that customised approaches will be required to meet the diverse needs in the broad region that is Champlain.

In Response

The continuum of patient needs are met by a variety of agencies and professionals along the journey from a range of sectors including long-term care, hospitals, community support services and other community partners, mental health and addictions, primary care, in-home care (CCAC and other providers), complex continuing care and residential hospices.

The Regional HPC Program will link with existing groups that understand the needs and effective means of managing those needs to implement a comprehensive, holistic program and to ensure ongoing engagement.

f. What do we mean by ‘Hospice Palliative Care’

What We Heard

Many of the Working Groups that were established as part of the planning process struggled with the definition of ‘palliative care’ and what is meant by the ‘palliative care approach’. The Plan supports that basic palliative care can be offered in any setting and at any time during the course of an illness and that it should be delivered by any health professional as part of their

caring for individuals with life limiting illness with access to secondary and tertiary support as needed. Through the stakeholder engagement process, it was discovered that the planning document did not go into enough detail to address these concepts and there was poor understanding of what is meant by ‘hospice palliative care’.

It was also noted that the term ‘hospice’ may have a negative connotation when translated into French.

In Response

A more detailed description of this terminology including case examples will be added to the planning document. The need for meaningful and accessible educational activities is repeatedly emphasized and will be addressed.

g. Supporting, Building and Enhancing Relationships

What We Heard

Within HPC, services are provided by a range of health service providers, informal caregivers and volunteers, and through a number of organizations. As with any large and complex system, relationships, both inter-personal and inter-organizational, need to be supported and sustained. Where relationships have been strained, all parties must dedicate selfless efforts to ensure a collaborative and team approach to focus on the interests of the individual as the primary goal.

Enhanced communication and transparency contribute significantly to the fostering of trust and the nurturing of these important relationships. Individuals involved in decision-making within the new Program need to be identified based on their competencies and skill sets, but avenues for service sector input and stakeholder consultation need to be maintained and enhanced to ensure a broad range of engaged voices.

Many have indicated that “success will depend on the level of true commitment from all those involved” more than on “formal agreements” that may seem to foster a “lack of trust” more than “incite collaboration”.

In Response

Ongoing communication and stakeholder engagement will be considered a priority as details with respect to the implementation of the Plan unfold. Processes for stakeholder input will also be put in place as a formal aspect of the Regional HPC Program.

5. IN SUMMARY

As described in this brief report, discussions with key stakeholders have provided valuable information to assist us in improving the Regional HPC Program Plan. We feel that through this process, we have heard from the community that we have produced a Plan that will result in an improvement to the current service system and that the community is willing to assist us with its

implementation. The Plan, with the changes as suggested in this document, will go forward to the Champlain LHIN board for their approval in May 2010.

It is important to note that this will not be the only time stakeholder input will be requested. The Champlain HPEOLC Network is committed to ongoing engagement with individuals and organizations that have a stake in, or will be impacted by, the implementation of the recommendations put forward in the regional planning document.

ATTACHMENT 1

STAKEHOLDER ENGAGEMENT TARGETED OUTREACH

Facilitated sessions were held with the following groups:

Client/Family Member/Volunteer Groups

Friends of Hospice Day Program Clients/Family Members/Volunteers (2 sessions)

Hospice at May Court Day Program Clients/Family Members/Volunteers (2 sessions)

Regional Cancer Program Patient Advisory Committee

Communities of Care Advisory Forums

Eastern Counties and Akwesasne Community of Care Advisory Forum

Ottawa East Community of Care Advisory Forum

Ottawa Centre Community of Care Advisory Forum

Ottawa West Community of Care Advisory Forum

Renfrew County Community of Care Advisory Forum

North Lanark North Grenville Community of Care Advisory Forum

End of Life Networks

Champlain Hospice Palliative and End of Life Network

Eastern Counties End of Life Network

Ottawa End of Life Network

Renfrew County End of Life Network

Other

Membership of all Working Groups involved in the development of the Regional Plan

Rogers House Board of Directors

Bruyère Continuing Care - Senior Administration

The Ottawa Hospital Palliative Care Consultation Team

Champlain CCAC Case Managers

University of Ottawa - Division of Palliative Care

Service Provider Agency Representatives including:

- Access Health Care
- At Home Hospice
- Saint Elizabeth Health Care
- Gem Health Care
- Community Nursing Registry of Ottawa
- We Care Home Health Services
- Bayshore Home Health (Ottawa, Eastern Counties)
- Carefor Home, Health and Community Services

Additional Feedback

The draft Regional HPC Plan and invitation to provide comment via SurveyMonkey link was distributed widely via email using a purposive and 'snowball' sampling approach. Le réseau des services de santé en français de l'Est de l'Ontario assisted in notifying French language service providers about the opportunity to provide a response to the Regional HPC Program Plan

The distribution list included targeting illness specific and health care related societies, organizations and agencies in Champlain including:

- | | |
|--|-------------------------------------|
| Regional Geriatric Advisory Committee | Council on Aging - Ottawa |
| Alzheimer Society | Champlain Community Support Network |
| ALS Society | Cancer Society |
| Coalition of Community Health and Resource Centres | Lung Association |
| Heart and Stroke Foundation | Parkinson's Society |
| MS Society | Kidney Foundation |

A response document was also received from the Community Palliative Care Network

ATTACHMENT 2
SURVEYMONKEY RESPONDENTS LIKERT SCALE RATING

	Strongly agree	Agree	No opinion	Disagree	Strongly disagree	Response Count
Foundational Recommendations	14	16	0	2	1 ⁱ	33
Key Elements	16	15	1	1 ⁱⁱ	0	33
Priority Recommendations-Access	22	11	1	0	0	34
Priority Recommendations-Resourced System	16	13	2	2 ⁱⁱⁱ	0	33
Priority Recommendations-Evidence-Based	19	10	2	0	2 ^{iv}	33
Priority Recommendations-Indicators	15	13	2	3 ^v	0	33
Priority Recommendations-Primary Care	20	13	1	0	0	34
Priority Recommendations-Standards/Competencies	18	13	0	2	0	33
Priority Recommendations-Knowledge	19	11	2	1	1 ^{vi}	34
Priority Recommendations-Overall	16	13	2	1 ^{vii}	0	32
Feedback – Francophone Community						
Recommandations fondamentales	5	0	0	0	0	5
Éléments clés	4	1	0	0	0	5
Recommandations prioritaires-accès	4	1	0	0	0	5
Recommandations prioritaires-ressources adéquates	4	0	1	0	0	5
Recommandations prioritaires-pratiques exemplaires	3	2	0	0	0	5
Recommandations prioritaires-indicateurs	5	0	0	0	0	5
Recommandations prioritaires-soins primaires	3	2	0	0	0	5
Recommandations prioritaires-normes et compétences	4	1	0	0	0	5
Recommandations prioritaires-connaissances	4	1	0	0	0	5
Recommandations prioritaires-dans l'ensemble	3	2	0	0	0	5

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- ⁱ Although reasons are difficult to identify, some of the comments for this question express concerns that the Leadership Committee revolves too much around the “tertiary services” and that formal agreements should not be utilised.
- ⁱⁱ One person expressed disagreement with “centralised governance”.
- ⁱⁱⁱ The discomfort seems linked to unknown decision makers and to scepticism that funding from acute care would be available and actually be reallocated.
- ^{iv} There appears to be some strong disagreement with Long Term Care and “tertiary services” being an initial priority with concerns expressed that other areas should be addressed as “urgently”. The continuum should be more strongly featured in these recommendations.
- ^v Some worry that the process will be unduly burdensome and not result in improved care. Also, there is concern that some important indicators (soft factors) are not easily measured and therefore ignored.
- ^{vi} There are concerns that too many resources will be dedicated to program development and process with little left for actual learning. Some seem to perceive “an educational program” as a central control measure.
- ^{vii} It may be that the Plan did not convince some that the Regional Hospice Palliative Program will be based on primary care and not focussed on meeting the needs of tertiary care providers.