

# **Advancing High Quality, High Value Palliative Care in Ontario**

## **DECLARATION OF PARTNERSHIP AND COMMITMENT TO ACTION**

**December 8, 2011**

## Transmittal

This *Declaration of Partnership and Commitment to Action* is the result of a collaborative effort from over 80 stakeholders from across Ontario who bring a wide range of insights and expertise to the table. We have achieved a common consensus on a vision for palliative care in Ontario. This work outlines the steps we need to take together to make that vision a reality.

There is no single author – we are all contributors and accountable to advancing this common vision through our individual and collective actions.

Each participant will use this tool to help inform change within his/her realm of influence and control. Similarly, the Local Health Integration Networks can choose to use this as a tool to help inform regional planning and the Ministry of Health and Long-Term Care can choose to use this as a tool to help inform policy decisions and system-wide planning.

Our expectation is that we use this document as a framework for all participants to engage more broadly with our colleagues and stakeholders. We should not lose focus of the ultimate goal of greater system integration that puts the person and their family at the core of every decision we make.

On behalf of the more than 80 participants from all sectors, professions and regions of the Province, Co-chairs from the **Leadership Collaborative** and the four **Theme Groups** are pleased to share this work:

### Leaders Collaborative

---

Susan Paetkau (co-chair)  
*Director, Health Program and  
Care Standards Branch, Health  
System Strategy and Policy  
Division, Ministry of Health and  
Long-Term Care*

---

Gary Switzer (co-chair)  
*Chief Executive Officer, Erie St.  
Clair Local Health Integration  
Network*

---

Jan Kasperski (co-chair)  
*Chief Executive Officer, Ontario  
College of Family Physicians*

## Care pathing across continuum of Chronic Disease Management

---

Julie Darnay  
*Director, Hamilton Niagara  
Haldimand Brant Hospice  
Palliative Care Network*

---

Dipti Purbhoo  
*Senior Director, Client  
Services, Toronto Central  
Community Care Access  
Centre*

## Integration and Shared Care Engagement Table

---

Julie Foley  
*Lead, Integrated Client Care  
Project, Ontario Association of  
Community Care Access  
Centres*

---

Dr. Mary Lou Kelley  
*Professor, School of Social  
Work & Northern Ontario  
School of Medicine, Lakehead  
University*

---

Dr. Denise Marshall  
*Associate Professor, Division  
of Palliative Care, Dept of  
Family Medicine  
Assistant Dean, Program for  
Faculty Development, Faculty  
of Health Sciences, McMaster  
University*

## Accountability and Governance

---

Dr. Nancy Merrow  
*Chief of Staff, Southlake  
Regional Health Centre  
Chair, Central LHIN Palliative  
Care Network*

---

Beth Lambie  
*Director, Erie St. Clair  
End-of-Life Care  
Network*

## Education, Mentorship and Specialized Support

---

Cathy Joy  
*Palliative Pain and Symptom  
Management Consultant,  
Waterloo Region*

---

Marg Poling  
*Palliative Pain and Symptom  
Management Consultant, North  
West Community Care Access  
Centre*

Participants of the Leadership Collaborative include (note: the full list of contributors to this document can be found in the Appendix):

Susan Paetkau (co-chair)  
*Director, Health Policy and Care  
Standards Branch, Health System  
Strategy and Policy Division, Ministry of  
Health and Long-Term Care*

Gary Switzer (co-chair)  
*Chief Executive Officer, Erie St. Clair  
Local Health Integration Network*

Jan Kasperski (co-chair)  
*Chief Executive Officer, Ontario College  
of Family Physicians*

Hsien Seow (writer)  
*Cancer Care Ontario Research Chair in  
Health Services Research  
Assistant Professor, Dept of Oncology,  
McMaster University*

Rick Firth (moderator)  
*Executive Director, Hospice Palliative  
Care Ontario*

Lori Adler  
*Manager, Practice Standards, College  
of Nurses of Ontario*

Stacey Daub  
*Chief Executive Officer, Toronto Central  
Community Care Access Centre*

Dr. John Hirdes  
*Professor, School of Public Health and  
Health Sciences, University of Waterloo  
Home Care Research Chair*

Elaine Gibson  
*Vice President, Complex, Specialty  
Aging and Rehabilitative Care,  
Parkwood Hospital*

Dr. Lawrence Librach  
*Professor and Head, Division of  
Palliative Care, Department of Family &  
Community Medicine, University of  
Toronto*

Andrea Martin  
*Lead, Waterloo Wellington Hospice  
Palliative Care  
Co-Chair, Quality Hospice Palliative  
Care Coalition of Ontario  
Co-Chair, Provincial End-of-Life Care  
Network*

Bill MacLeod  
*Chief Executive Officer, Mississauga  
Halton Local Health Integration Network*

Melody Miles  
*Chief Executive Officer, Hamilton  
Niagara Haldimand Brant Community  
Care Access Centre*

Margaret Mottershead  
*Chief Executive Officer, Ontario  
Association of Community Care Access  
Centres*

Dr. Christine Newman  
*Paediatric Palliative Care Physician,  
SickKids Hospital*

Gail Paech  
*Chief Executive Officer, Ontario Long-  
Term Care Association*

Kathryn Pilkington  
*Director of Professional Services and  
Health Policy, Ontario Association of  
Non-Profit Homes and Services for  
Seniors*

Sue Thorning  
*Chief Executive Officer, Ontario  
Community Support Association*

## Table of Contents

Charter for Advancing High Quality, High Value Hospice Palliative Care in Ontario .....	6
Hospice Palliative Care Definition .....	7
Vision .....	9
Values and Assumptions.....	9
Achieving the Vision.....	11
Shifting to a New Delivery Paradigm .....	11
Key Issues: Gap between current state and the new model .....	17
Moving Forward: Incremental, Opportunistic Change Strategy .....	19
Strategy Map .....	20
Key Success Measures .....	21
Balanced Scorecard Approach .....	22
Broader Success Measures.....	23
COMMITMENT TO ACTION .....	24
Appendix A: Definitions .....	49
Appendix B: What Success will Look like and Roadmap for Broader Health System Transformation .....	53
Appendix C: Environmental scan of the current state in Ontario .....	56
Current Data Overview .....	56
Gap between current palliative care delivery system and desired future state .....	59
Appendix D: Workgroup Participants.....	67
Integration and Shared Care .....	67
Accountability and Governance .....	68
Education, Mentorship and Specialized Support .....	69
Care pathing across continuum of Chronic Disease Management .....	70
Project Management Team .....	71

# **Charter for Advancing High Quality, High Value Hospice Palliative Care in Ontario**

## **How we as organizations, leaders and care providers agree to work together to improve quality and the value of health care delivery for Ontarians**

We are a partnership of individual, family, professional, volunteer, policy, planning and research representatives of Ontario's health care and hospice palliative care community (the "partners") that are committed to working together to advance high quality, high value health care and palliative care delivery for Ontario residents and their families.

As partners, we share a common purpose to better support adults and children with life-limiting illness, their families and their caregivers to improve their comfort, dignity and quality of life preceding death. This support extends to families and caregivers following a loved one's death. Achieving this purpose requires collaboration and commitment with shared ownership of solutions and actions between all partners and across all care settings.

How we treat those who are living with or dying from life-limiting illnesses in our community reflects who we are as a society. All Ontarians have the right to quality palliative care, which includes the right to optimize the quality of their life, to have access to physical, psychological, social, bereavement and spiritual care, to have respect consistent with other phases of life, and to die with dignity.

We aim for the delivery of quality care that is needs-based, proactive, holistic, timely, on-going, consistent, connected and respectful to improve the individual's and family's experience of care as well as population health and system outcomes. We support an integrated continuum of care options, recognizing the important role that care settings such as primary care, home care, long-term care homes, hospitals (acute and other), community support services and residential hospices all play in providing care to adults and children with progressive life limiting illness.

We believe that where desired by dying people and whenever possible, people should receive care and support to the end of their lives in their home community through primary providers<sup>1</sup> in any care setting, with access to specialty care where appropriate.

We will work together to strengthen the ability of primary providers across all care settings to effectively serve adults and children with a wide range of needs, diseases and conditions, based on a holistic view of the person along a psychosocial continuum of care, along with a realistic understanding of their support environment. We will work together to support primary delivery by ensuring appropriate access to information,

---

<sup>1</sup> Refers to all providers in any sector who offer first level or first response contact with individuals in relation to their health, including physicians, nurses, PSWs and others – see definition in appendix A

education, mentorship as well as regionally organized specialized palliative care services in all regions and local communities.

While many chronic diseases are life limiting, individuals with advanced chronic disease<sup>2</sup> (i.e. those likely to be entering their final year of life as evidenced by severe and progressive symptoms or decreased functional status) or end-of-life care needs especially require high quality palliative care and support.

In terms of immediate focus, partners agree that adults and children with advanced chronic disease and their families should be targeted for delivery improvements first, as they will benefit most from the actions outlined in this paper, and currently represent a higher risk for poorer quality of life and system outcomes. At the same time, we will promote dialogue with families and caregivers, professionals who serve individuals with chronic disease, and the public about palliative care generally and about advanced care planning to broaden awareness and improve access to available supports and resources earlier in an individual's disease trajectories. Our focus is to optimize the best of what is currently available ("art of the possible") while building for the future. We recognize that any reforms adopted must lead to better value for money through improved efficiencies and greater productivity, as well as improved quality.

We are approaching our palliative care partnership as a foundation for broader health care transformation and not as a unique project for a specialized population - see Appendix B for a description of what we imagine success to look like for the system as well as an initial roadmap to transform delivery within existing programs and structures.

This Declaration of Partnership sets out our collective commitments, common priorities and appropriate actions to optimize care delivery to improve the individual and caregiver experience, quality and value for the system. It identifies the need and next steps to better achieve equitable access to safe, comprehensive and high quality care and support for individuals and families across Ontario. We are committed individually and collectively to moving forward with implementation of recommended actions – both immediately and in the longer-term.

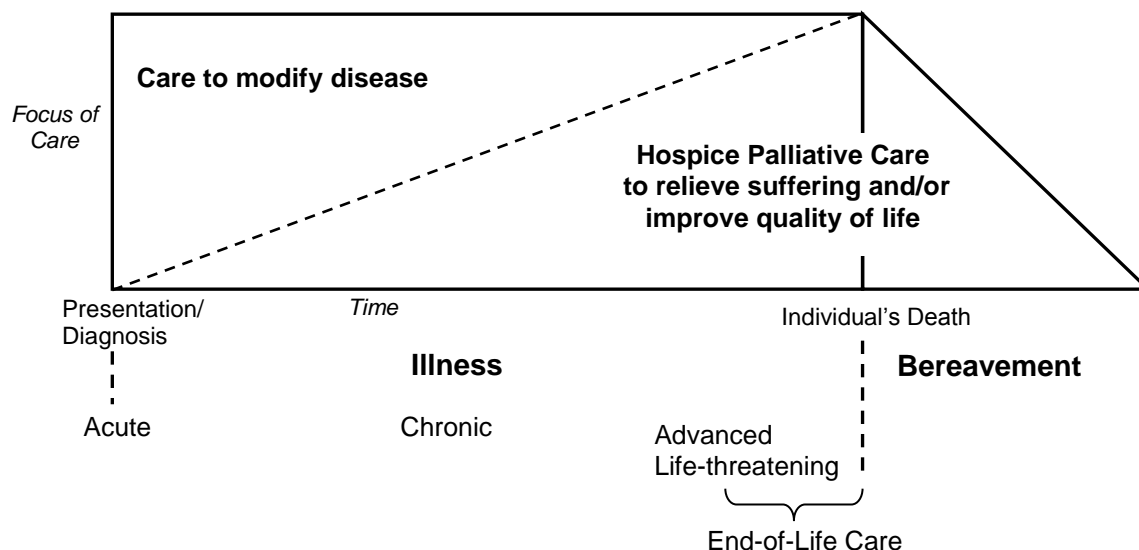
## **Hospice Palliative Care Definition**

Hospice palliative care is a philosophy of care. Residential hospice care reflects a care setting. For the purposes of this work, the terms "hospice palliative care" and "palliative care" will be used interchangeably.

**Our definition and understanding of hospice palliative care is adapted from the Canadian Hospice Palliative Care Association (CHPCA) Model to Guide Hospice Palliative Care (2002):**

---

<sup>2</sup> See Appendix A for definitions



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

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement
- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care:

- Is appropriate for any individual and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care
- May complement and enhance disease-modifying, restorative or rehabilitative care or it may become the total focus of care
- Is most effectively delivered by an inter-professional team of healthcare providers skilled in all aspects of the caring process related to hospice palliative care that may include unregistered staff.
- Is most effectively provided when the care is integrated at the clinical, organizational and overall system level.
- Is person and family centred, respecting their social, spiritual and cultural practices.
- Includes end of life care but is not limited to the time immediately preceding death.

In terms of the level of palliative care needs within Ontario's population, we note that there are three typical trajectories leading to death.

- The first trajectory is sudden death from an unexpected cause, such as an accident or homicide (or about 10% of all deaths.)



- The second trajectory is the steady decline in health status from a progressive and predictable disease with a “terminal” phase, such as cancer (or about 28% of Canadian deaths).
- The third trajectory is advanced chronic illness marked by slow decline with periodic crises that may result in sudden death. The vast majority of deaths arise from advanced chronic diseases such as heart disease, stroke, chronic obstructive pulmonary disease, renal failure, and Alzheimer's disease and fit in this third trajectory.

It has been estimated that only 16-30% of Canadians have some level of access to palliative care and support appropriate to their needs, and the majority of individuals that do have access often have a diagnosis of cancer (Carstairs, 2010).

## Vision

Adults and children with progressive life-limiting illness, their families and their caregivers will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to help them live as they choose, and optimize their quality of life, comfort, dignity and security

## System Goals (Triple Aim)

### **QUALITY:**

*Improve client/family, caregiver and provider experience by delivering high quality, seamless care and support*

### **POPULATION HEALTH:**

*Improve, maintain and support quality of life and health status of people with progressive life-limiting illnesses to the extent possible*

### **SUSTAINABILITY:**

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

## Values and Assumptions

The following assumptions have guided the development of our vision and action plan.

**All Ontarians should have equitable access to high quality care and support to optimize their ability to live well with a progressive life-limiting illness wherever they reside or receive care.**

- All people of all ages (children and adults) living with progressive life-limiting illnesses, and individuals coping with complex grief, fall within the scope of this vision and declaration.
- Palliative care is not just for individuals in the final months of life and is not limited to cancer diagnoses.

- Quality palliative care should be integrated with quality chronic disease management for all individuals living with progressive life-limiting illnesses. There is a need for better, coordinated care planning along the entire chronic disease trajectory and aging process. This includes early and on-going advanced care planning.
- Includes culturally and linguistically diverse, and vulnerable populations
- Includes every care setting where Ontarians reside or die. It can be provided at home (and in all home settings, for example, retirement homes, group homes, etc.), in hospitals, long-term care homes, free-standing hospices, and so on, and includes all services that are received.
- Geography includes urban, rural and remote and First Nations communities (both reserve and urban).
- When death is inevitable, every effort is made to have a person die with dignity and in peace and comfort, based on individual and family choice and preferences.
- Includes bereavement support to assist informal caregivers, residents, and providers (front-line staff) with the management of grief, regardless of the cause of death.

**The individual with a progressive life-limiting illness and their family are at the centre of care**

- Care is client-directed (through the individual themselves or their substitute decision makers, and advanced care planning) and client-centred (through the way care providers organize themselves to provide comprehensive care).
- Equally important is that care is family-centred
  - Family members will be key recipients of care, both before and after a loved one's death.
  - Family is inclusive of all relationship types that are acknowledged by the individual (e.g. relative, partner, friend, etc.).

**Family members, friends and community groups (informal caregivers and volunteers) willingly provide the majority of care for most individuals.**

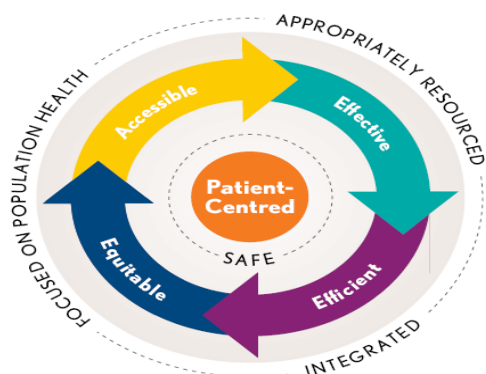
- The most appropriate and sustainable system is one that includes support for informal caregivers and volunteers to help them be successful and effective in this role.

**Quality is a key driver to achieve system goals**

In the context of this declaration, quality means:

- Care and support centres on the person and their caregivers
- Every Ontarian with a life-limiting illness and their family/informal caregivers will be able to access care and support that is safe, equitable, appropriate, effective and efficient
- The system providing this care and support is population-focused, appropriately resourced, and integrated

### Nine Attributes of a High-Performing Health System



© Ontario Hospital Association and Ontario Health Quality Council, 2009

### Increasing sustainability and value is a central focus of improvement

- Sustainability is enhanced by delivering better value for Ontarians and our health system, as evidenced by improvements in population outcomes and system performance relative to cost.
- Value will be most improved to the extent we can optimize existing available resources at the primary level to provide proactive, holistic care and preserve specialist delivery for the small number of individuals with highly complex needs.
- Any reforms adopted should lead to better value for money through improved efficiencies and greater productivity, as well as improved quality. In particular, unnecessary new administrative structures will not be added to the system. The value of any new structure, initiative, program or investment should be measured and reported in terms of the extent that they contribute to improving population outcomes and system performance relative to cost. The unit of value measurement is the person.
- Sustainability as measured through “value” will be a primary lens applied to all proposed action items within the *Commitment to Action* and will become a primary component of evaluation as the health system evolves.

## Achieving the Vision

### *Shifting to a New Delivery Paradigm*

“The true test of a health care system is how well it serves the people who need it most. We must move beyond a system organized around acute illness and reactive management of disease to one that deals effectively and proactively with chronic illness and the needs of an aging population.”<sup>3</sup>

The evidence is overwhelming that excellent palliative care has the same elements as excellent chronic disease management. Ontario’s health care system needs to shift to a single, cohesive delivery model that integrates care and support for adults and children

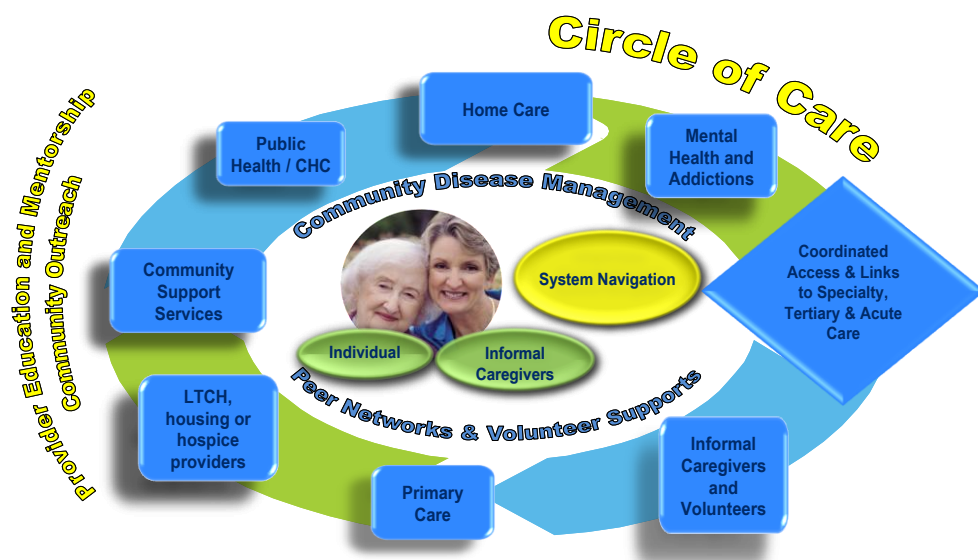
<sup>3</sup> Donald M. Berwick, MD, President and CEO Institute for Healthcare Improvement

with chronic disease across the full care and support continuum from diagnosis until death and through bereavement including access to quality palliative care.

**Current Model:** individuals with advanced chronic disease(s) or complex care needs receive care that is reactive, targeted, disease-focused, centering on curative treatment, and delivered by multiple, siloed, individual providers in distinct, acute episodes.

**Proposed new model: Virtual extended inter-professional teams**

Adults and children with advanced or EOL chronic disease(s) and their informal support network will receive care and support that is proactive, holistic, person and family-focused, centering on quality of life and symptom management issues, and delivered by a virtually integrated inter-professional team in a coordinated, continually-updated care plan, that encompasses all care settings in which the client receives care.



We intend to transform delivery to develop a comprehensive, integrated continuum of care and support that wraps delivery around the adult or child, and their family and informal caregivers and responds to his/her goals, needs and personal contexts through a virtual extended inter-professional team. Moving to the new model requires that:

1. A full continuum of care settings and services is in place;
2. In each care setting where individuals die, there is a clearly defined care program that embeds a palliative care philosophy and approach;
3. Sectors and services are linked by common practice, processes, structures and education;
4. Adequate numbers of trained professionals and trained volunteers are available;
5. System level accountability is clearly defined and communicated; and
6. Funding models, guidelines and policy directions support an integrated system

It also requires a new concept of team. The team approach outlined in this document extends team-based delivery that might already be available in primary care, home care or palliative care sectors by integrating existing teams or resources with each other where appropriate and connecting health care delivery with broader social supports within community, informal, social services, or municipal sectors. It includes designated resources to work with clients and caregivers (to the extent they are willing) on the development of an overarching care plan that outlines the roles and expected contributions of all formal and informal care and support providers. It assigns clear responsibility for the effective coordination, management and communication between extended team members, and tracking performance and outcomes.

We note that building an extended inter-professional team for each client will be greatly facilitated to the extent that dedicated, formal inter-professional primary chronic disease management teams and specialized palliative care consultation teams are already available within that community or care setting. Where teams exist, many of the connected providers will already have established team protocols, clear roles, and trusting relationships with each other.

### **Benefits for Individuals and Families**

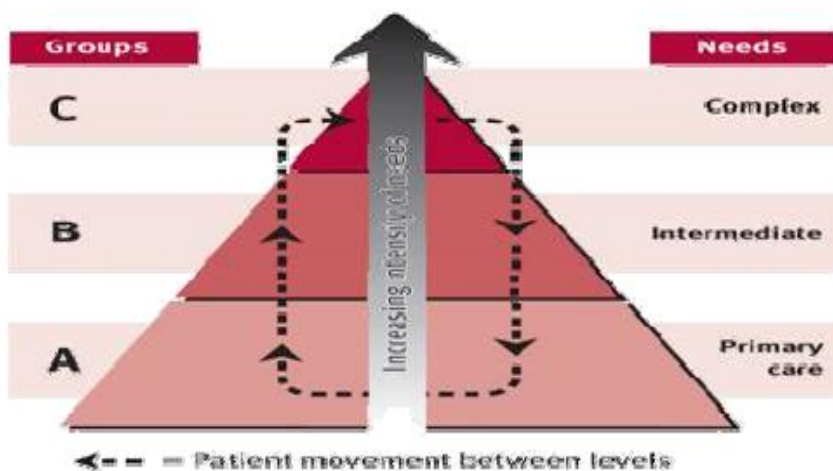
- The person's needs are identified early. Individuals and families are able to connect with the supports they require simply and with minimal wait times through designated care coordinators ("one-stop shopping approach").
- The individual and/or family designates are engaged as partners in all care planning and delivery decisions, as well as in the monitoring of outcomes
- Individuals receive care from one inter-professional team, which has capacity for 24/7 responsiveness. The team fits around the person/family needs (rather than fitting the individual into existing programs). The individual or substitute decision-maker gives permission for members to join the team as well as access and sharing of information.
  - Medical, clinical and professional services such as physicians, nurses, hospice staff and volunteers, psychosocial/spiritual support, rehabilitation specialists and therapists, as well as personal support workers and homemakers, day programs, Meals on Wheels, transportation and social programs are integrated when needed as part of the team. Members of the team communicate effectively among each other and continually update the care plan as necessary.
  - Specialized services and supports are brought into the team as needed. In addition to hospice palliative care specialists, other specialist members might include disease specialists, cognitive and behavioural support, and mental health and addictions, for example.
  - Whenever the person is admitted to hospital, hospital staff enter the person's circle of care and collaborate with the community team to ensure the person returns to the community as quickly as possible with appropriate transitional supports.
  - Home-based palliative care will be part of primary care and chronic disease management, supporting individuals who desire to remain in their communities until the end of their life.

- Individuals and their caregivers are fully informed about what medications to take, what signs to watch for, and when to seek additional care. Families/caregivers know who to contact to deal with issues that arise after normal business hours
- Consistent staff and volunteers visit the individual to the greatest extent possible
- The team shares a single client record, including medication information, to increase safety and so individuals and families do not have to repeat their information unnecessarily
- Flexible respite care is available when needed. Towards the end of life, the location of care will be optimized to achieve an appropriate balance between acuity, preference, convenience, and economies of scale (i.e. choice between home or residential hospice or hospital).
- The individual and family experiences care delivery as seamless, connected and continuous

In addition to the delivery changes described above, the partners to this declaration advocate and encourage a dialogue and action to enhance the availability of other key supports for informal caregivers at national, provincial, and business leader tables. For example, additional supports beyond delivery might include expanded cash-for-care or direct payment funding schemes, and more flexible job benefits or protections for compassionate care leaves.

### A person's needs may shift significantly over the episode of care

The following diagrams<sup>4</sup> provide an overview of how an individual's needs might change over the course of their disease, but not necessarily in a consistent or predictable pattern.

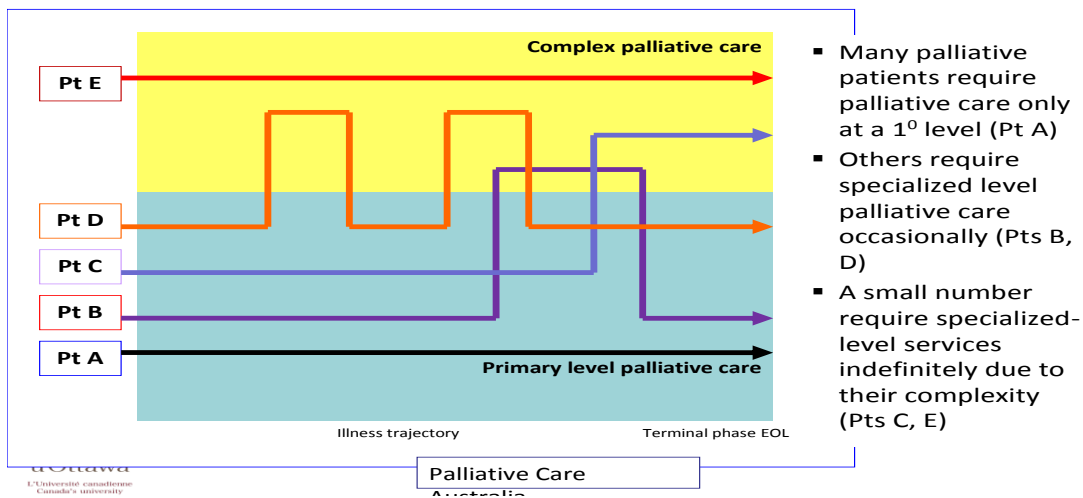


<sup>4</sup> Source – pg 13 -

<http://www.palliativecare.org.au/Portals/46/A%20guide%20to%20palliative%20care%20service%20development%20-%20a%20population%20based%20approach.pdf>.

## Levels of care for palliative patients

2



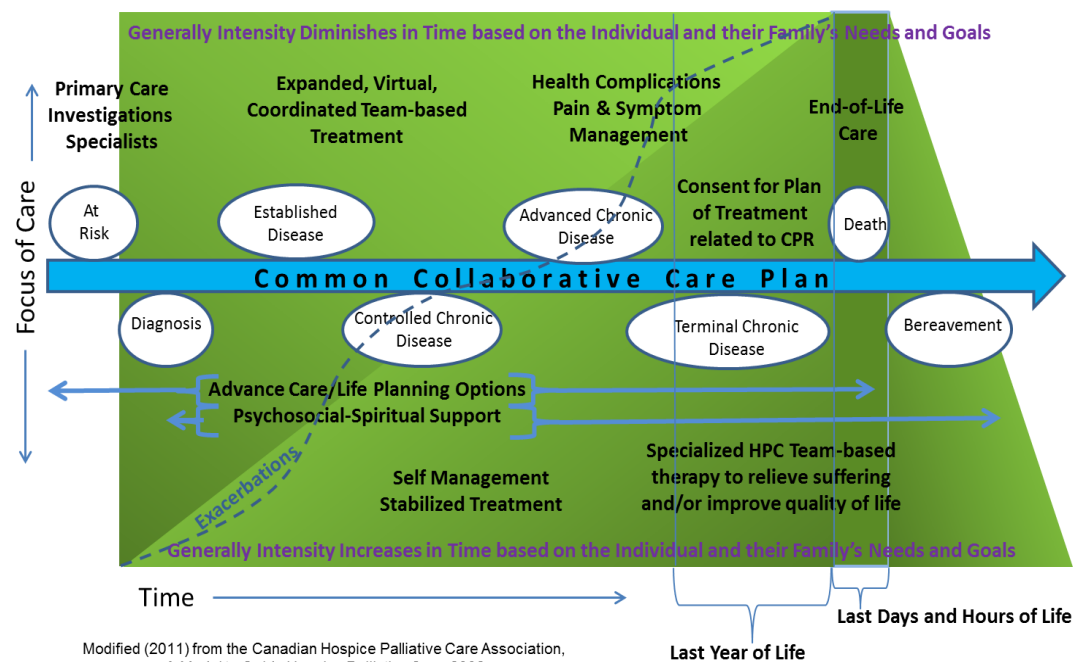
Source – pg. 17 adapted from :

<http://www.palliativecare.org.au/Portals/46/A%20guide%20to%20palliative%20care%20service%20development%20-%20a%20population%20based%20approach.pdf>

## Delivery must be equally fluid in response, with hospice palliative care philosophy and expertise well integrated with primary delivery and CDM

To enable the system to respond effectively to unpredictable and rapidly changing complex needs in a timely way

### CHILD & ADULT HOSPICE PALLIATIVE CARE - CHRONIC DISEASE CONTINUUM MODEL

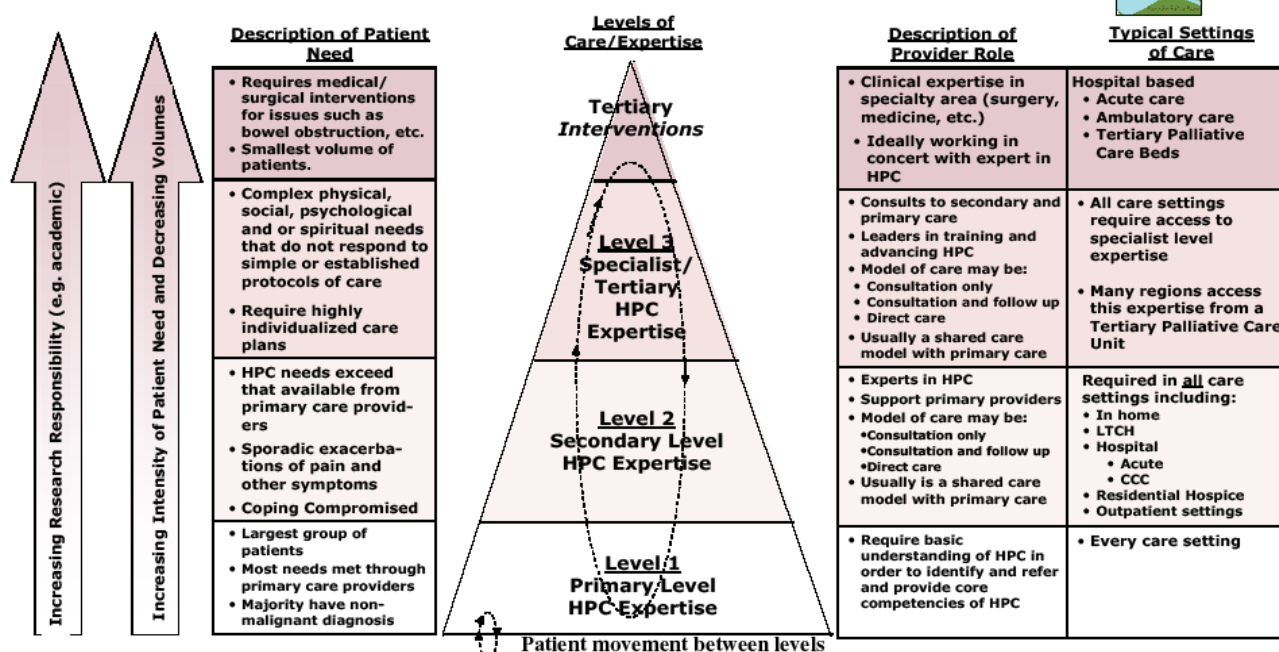




## Regionally organized specialist resources to support primary delivery provides best value for clients and the system

Specialized palliative and advanced chronic disease resources will be coordinated at a regional level through an organized program or network. The following conceptual model describes how primary and secondary level services can be integrated with specialist palliative care resources.

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



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

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

### Implications for Delivery

- For most individuals, families, informal caregivers and the individual's paid or volunteer networks provide a strong foundation of support. They will be acknowledged as key delivery partners on the team. They are entitled to and should expect to receive education, information, mentorship and support from their publicly funded delivery partners to equip and enable them to optimize their role on the team, and to minimize the burden and stress which can be associated with their caregiving role.
- Providers from multiple organizations, sectors and systems will be expected to coordinate their care and support delivery to focus on continuity<sup>5</sup> and the achievement of common goals.

<sup>5</sup> "Continuity" is the degree to which a person experiences a series of discrete health care services, supports or interventions as coherent, connected and consistent with their medical, clinical and psycho-social spiritual needs and personal context. Continuity of care is achieved by bridging discrete elements in one's care pathway – whether different episodes, interventions by different providers, or changes in



- All primary providers in all care settings have capacity, education and support to deliver excellent comfort, and pain and symptom management to all clients with progressive life-limiting illness as part of their normal care. In each setting where individuals die, a defined program exists for individuals with advanced / EOL chronic disease (primary level palliative expertise)
- Primary providers in all care settings have access where appropriate to dedicated palliative consultation teams, and other specialized palliative programs and resources, to support primary providers in effective management of their client's care needs, including information, education and mentorship support (secondary level palliative expertise).
- Tertiary level specialized resources and interventions are available to support individuals with highly complex care needs.

Key enablers critical to establishing the new model include strong community capacity (non-medical determinants of health), dedicated and responsive formal program and team resources in the community which can be drawn from to build the virtual extended team, standardized delivery processes, health human resource (HHR) capacity, technology support and strong governance and accountability mechanisms.

## **Key Issues: Gap between current state and the new model <sup>6</sup>**

### Access

Inadequate/ inequitable access to integrated, comprehensive, high quality pain and symptom management and comfort support

- Key care settings and services are lacking in many catchment areas, especially in rural, remote and First Nations communities (both reserve and urban)
- Some groups are under-represented and lack access to appropriate support and resources
- Individuals and caregivers have challenges locating effective navigation and access support
- Palliative care is poorly understood by individuals and caregivers, as well as by many service providers resulting in referrals being made too late in the disease trajectory or referrals not being made.

### Caregiver Support

- Key supports for families and caregivers are lacking or inconsistently available. This includes the bereavement aspect of palliative care.

### Service Capacity across all Care Settings

Significant disparity exists amongst Local Health Integration Network (LHIN) regions in terms of provision of complex care, advanced chronic disease management, hospice

---

health status – as well as by supporting aspects that endure intrinsically over time, such as the person's values and sustained relationships

<sup>6</sup> See the Appendix C for a more detailed environmental scan of current state delivery

palliative care, and end-of-life care. This regional inconsistency creates a provincial landscape in which care and support is piecemeal.

- Key program elements that are most frequently missing include:
  - Access to 24/7 palliative care expertise
  - Access to inter-professional expertise
  - Identified palliative care lead/champion/contact within every care setting
  - Clearly defined model of care delivery and formalized palliative care program
- There is a shortage of palliative care human resources with training in palliative care and grief and bereavement
- There is a lack of consistent and standardized education and training approaches
- There is a need to define the relative role of each care setting (residential hospices, long term care homes, home care and hospitals [acute and other) within the full continuum of care in Ontario.

### System Integration

Chronic disease management and palliative care are required and provided in multiple care settings. However, they are not necessarily integrated into a continuum of care that spans diagnosis to end of life to bereavement. Programs and services are variable across the province and act as stand-alone models that are not necessarily integrated amongst each other to care for the complete individual and their family.

- Specific integration essentials are lacking or inadequate in each region including: common clinical practices and processes across sectors (including use of common tools); shared functional and clinical infrastructures; and common education

### Accountability

Health and social care in Ontario is delivered by independent sectors and by independent service providers, each with its own Board of Directors, individual mandate, operational imperatives and strategic directions. Within this multi-sector context, overall shared accountability for the person and family and for the achievement of health system's triple aim goals is unclear:

- No endorsed/funded provincial level mechanism for standardization of clinical processes or system-design best practices
- Inadequate system-level accountability, evaluation, monitoring and reporting
- No provincial performance standards (note: development would need to recognize the need for local flexibility in how they are achieved)
- Funding does not follow the client through the care system
- Family and caregiver voices are not currently reflected in local and system level planning and governance.
- Lack of accountability based on outcomes (all levels).
- Lack of tracking and reporting on outcomes to drive change (all levels).
- Jurisdictional issues are a barrier to funding and service provision in First Nations communities.

## Public Awareness

- Lack of common public communication/messaging (including advance care planning)

Failing to address these issues results in:

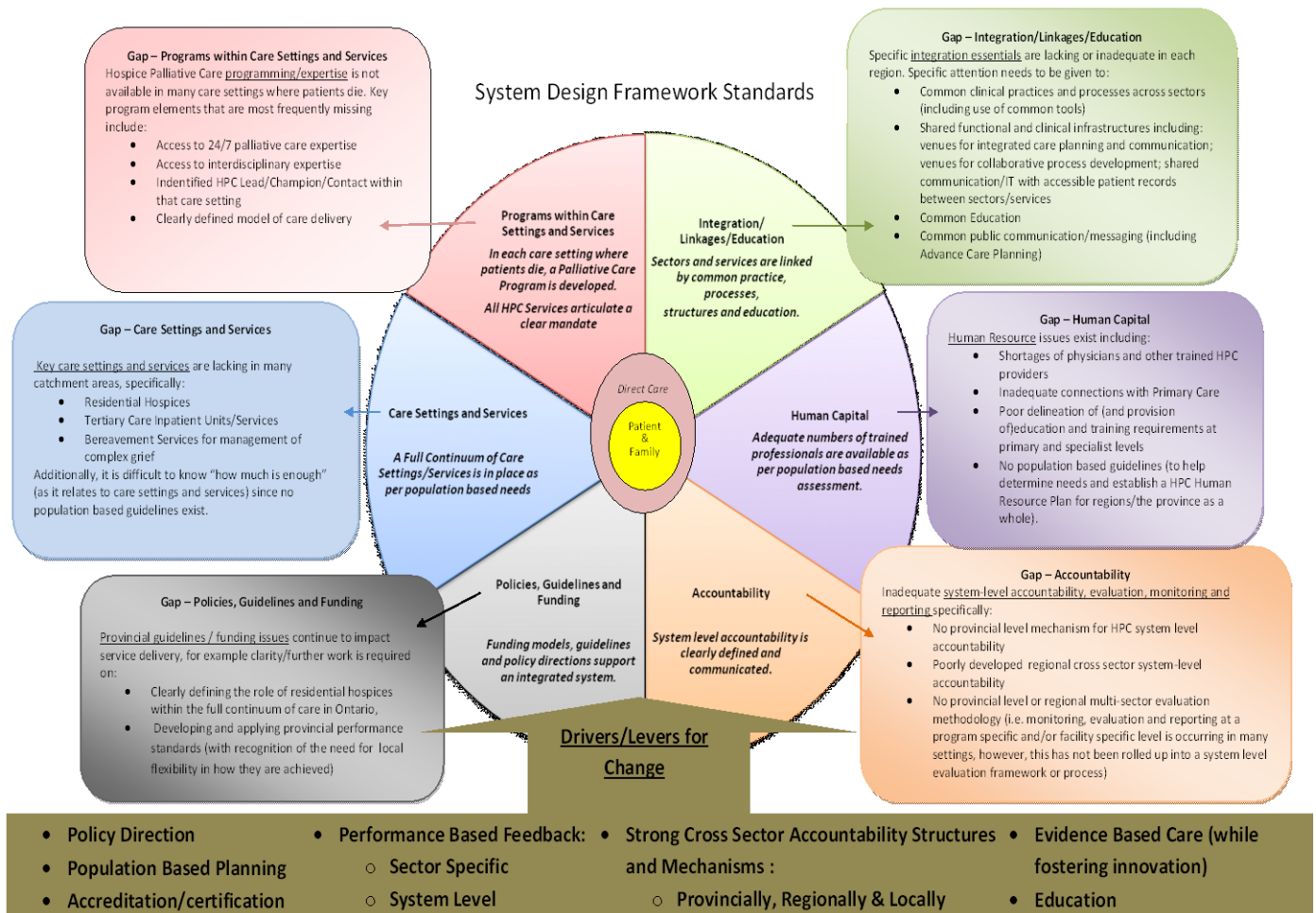
- Individual / family navigation issues
- Referrals being made very late in the disease trajectory (e.g. a few weeks or days before death)
- Referrals not being made for individuals with chronic disease diagnoses (e.g. non-cancer diagnoses)
- Increased individual and family burden
- Lack of congruence between individual's actual location of death and location of choice
- Inability to respond adequately to culturally/linguistically diverse populations as well as urban/rural/remote populations and First Nations communities (both reserve and urban).
- Lack of PC expertise and specialized resources for long term care homes and primary care settings.
- Fragmentation of care (poor continuity of care, redundancy of processes)
- Increased expense to the health care system (due to: poor care transitions, prolongation of expensive treatments which may neither prolong nor improve life, unnecessary emergency department and inpatient hospital utilization, etc.)

## **Moving Forward: Incremental, Opportunistic Change Strategy**

***Key Strategic Drivers: QUALITY ~ COST ~ LEADERSHIP***

Addressing key issues supports an initial focus on improving a number of the existing structures (for example, caregiver supports, system capacity, governance) and processes (for example, best practice adoption, integration, innovation) in order to advance chronic disease management and palliative care delivery to improve person-centred quality-related outcomes (for example, access, individual and family experience, and clinical outcomes such as pain and symptom management). By focusing on these areas initially, key population and system performance outcomes should be improved. Key strategic drivers or levers of change include quality and financial incentives as well as strong change management/leadership.

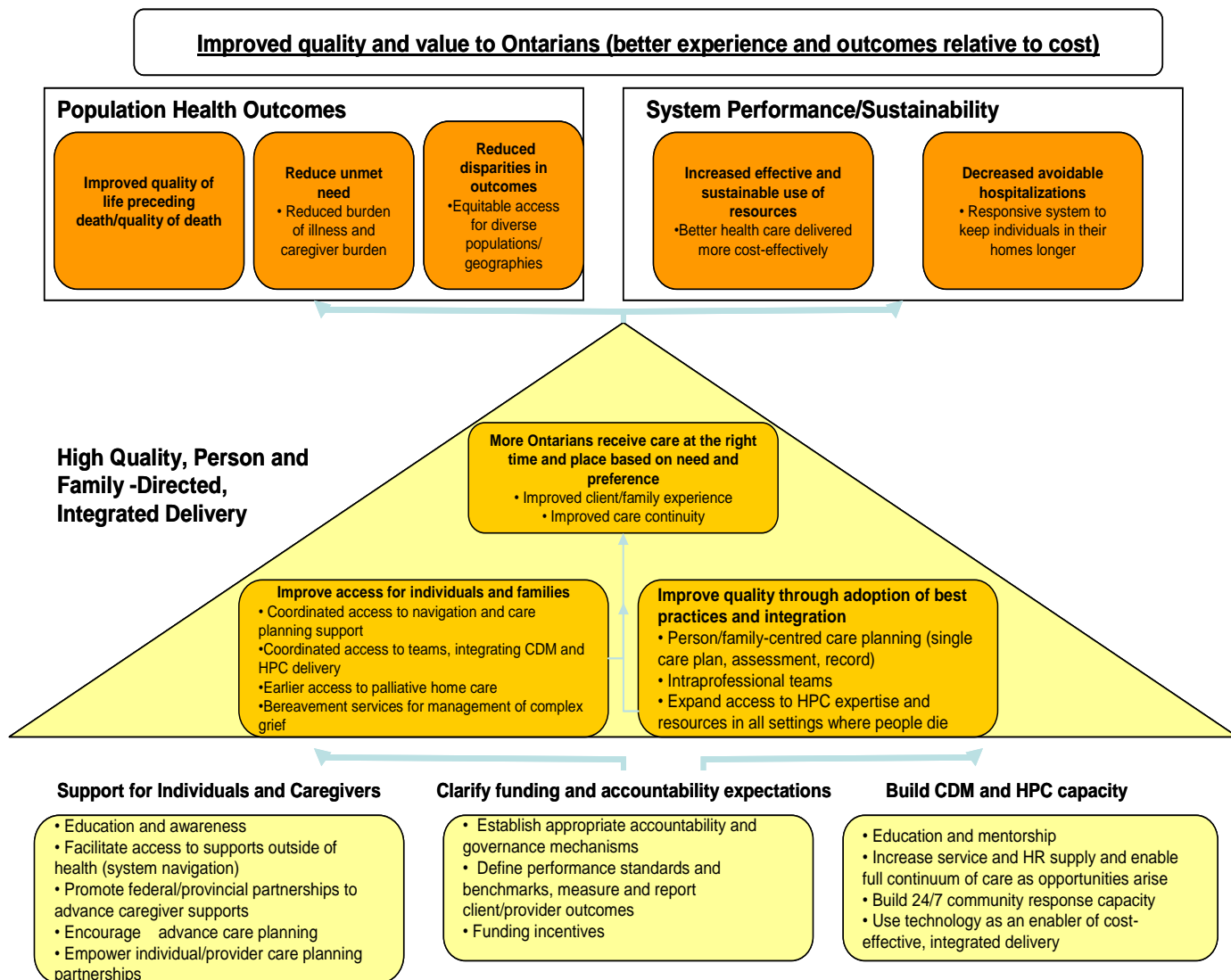
**Schematic Showing Gap between Current State and System Design Framework Standards with Levers/Drivers for Change**



**Strategy Map**

This *strategy map* diagram documents the primary strategic goals being pursued through this engagement. The creation of a strategy map is generally the first step in pursuing a balanced scorecard methodology. It defines focus areas and objectives and highlights broad relationships or direction of anticipated causality between objectives. In this map, objectives are arrayed across three horizontal bands on the strategy map. The bottom and middle bands represent the necessary structures and processes respectively that need to be improved in order to achieve the desired population and system performance outcomes (the third band) to create value for Ontarians.

## Palliative Engagement Strategy Map



## Key Success Measures

A strategy to measure better quality delivery and success in relation to improved population and system outcomes needs to start from the fundamental principle that the person is the unit of value creation in health care delivery:



A shift towards a new delivery model should be designed to achieve a balanced set of outcomes: improved quality (individual, family and provider experience); improved population health (improved quality of life); and, improved system performance/sustainability.

## ***Balanced Scorecard Approach***

Four measures are proposed here for initial / immediate development and tracking in all care settings in which it is currently available, while building capacity to track standardized data across all care settings:

1. Change (decrease) in caregiver burden
  - Note: More investigation on data quality would be pursued:
    - Currently, indicators can be applied to only a subset of care settings: LTCHs, complex continuing care (CCC), home care clients, etc. Individuals receiving services in acute settings, e.g., acute care and ER, and palliative patients living in the community under the care of GP/FP (without home care) will not be captured.
  
2. Change in location of Ontario deaths (at home <sup>7</sup>) relative to benchmarked performance (baseline or comparator across organizations or jurisdictions)
  - This is a measure that would apply to the entire continuum of care.
  - Note: More investigation on data quality would be pursued:
    - There is currently a three year lag in reporting of deaths by Ontario Registrar General. As such, this indicator will not be able to reflect real-time process improvement, however, it could be used as an outcome indicator.
    - Will need to further review quality of data that may impact validity.
  
3. Change (increase) in quality of life preceding death/quality of death
  - Note: More investigation on data quality would be pursued:
    - There is no existing data source for all care settings that can directly measure the quality of life of a population. However, there are objective measures that might enable us to use functional information as proxies for quality of life and quality of death. The use of proxies such as the RAI-MDS, RAI-HC, RAI-PC or RAI-PC-H could enable us to begin monitoring improvements in care settings that currently apply these functional assessments (e.g. LTCH, home care, etc.). Another option could be to implement existing surveys, or develop new surveys, both of which would require the creating of a new data holding across the province, testing/validation, training, etc.
  
4. Change (reduction) in: avoidable hospitalizations
  - Note: More investigation on data quality would be pursued:
    - Avoidable hospitalizations comprise preventable hospital admissions which are usually measured with indicators such as admissions for ambulatory care sensitive conditions (ACSCs) and preventable hospital readmissions measured by indicators such as the 30-day hospital readmission indicator.

---

<sup>7</sup> “Home” includes all home settings, for example, retirement homes, group homes, assisted living etc

- As such, this measure can be re-defined to the following two indicators and evaluated separately
  1. Change (reduction) in the rate of admissions for ambulatory care sensitive conditions (ACSCs) for palliative patients
  2. Change (reduction) in the rate of 30-day hospital readmission for palliative patients

Over time, we anticipate that all health providers will be measured and held accountable in terms of their ability to add value to health care delivery. We are proposing a blended accountability mechanism where all publicly funded providers - primary, secondary and tertiary - would share responsibility for achieving system and population outcomes, as measured through the identified indicators.

### ***Broader Success Measures***

The key measures identified above are a subset of success measures that should be pursued as part of a broader data and performance measurement strategy.

Comprehensive and real-time data collection, analysis and feedback are critical to driving continuous improvement in both direct care delivery as well as system design. While a number of measures may be important to providing a robust picture of performance, there is much analytical and infrastructure work that must be completed in order to establish a system-wide approach to monitoring and reporting.

#### **Initial process-based measures of success might include:**

Early process measures might include the number of integrated delivery teams, number of individuals and families receiving care and support through consultation and integrated delivery teams, number and type of professionals connected to the individual's care, number of organizations collaborating on a care plan, rates of improving advance care planning, access and uptake of education initiatives, etc.

#### **Initial quality-based measures of success might include:**

- Change (decrease) in caregiver burden \*
- Change (improved) individual, caregiver and provider experience \*
- Change (improved) pain and symptom management
- # of persons with advanced or EOL chronic disease receiving team-based care
- # of persons with advanced or EOL chronic disease discharged from hospital to team-based care (100% target)
- Change in location of Ontario deaths (at home) relative to benchmarked performance (baseline or comparator across jurisdictions) \*

In terms of the strategy map, this in turn should lead to improved population and system performance outcomes:

#### **Key Population Outcomes**

- Change (increase) in quality of life preceding death/quality of death \*

- Change (reduction) in unmet need (individual and family)
- Change (reduction) in disparities in outcomes across vulnerable populations and geographies and First Nations communities

### **Health System Impact**

- Change in costs per episode of care (cost/service efficiency)
- Change (reduction) in: unscheduled ED visits; ALC days; drug costs; 30-day and 90 day re-admissions; number of hospitalizations in the last month of life; length of hospitalization stay in the last month of life; deaths in hospital (cost avoidance in health care system) \*
- Change (increase) in # of organizations that offer palliative care programs

Ultimately, this drives value to Ontarians – improved population outcomes and quality (experience) relative to cost over time

NOTE: access and client number targets related to palliative care programs and services are challenging and have not been included here as it is assumed that system change moving forward will include all individuals with progressive life-limiting illnesses as opposed to those coded as end-of-life care within the current system.

## **COMMITMENT TO ACTION**

As family, professional, volunteer, policy, planning and research partners, we are committed to working together to advance high quality, high value health care and hospice palliative care delivery for Ontario residents and their families. We are committed individually and collectively to moving forward with implementation of recommended actions – both immediately and in the longer-term.

We share the belief that the priorities and actions outlined in this document will significantly enhance the quality and value of palliative care delivery in Ontario by improving person, caregiver and provider experience, enhancing quality of life prior to death, alleviating complex bereavement after death, reducing avoidable ER visits and hospitalizations, and better supporting people to die in their location of choice.

Where the action is within our own respective sphere of control to implement, we commit to implement this action as soon as practical.

We further commit to share knowledge and influence our colleagues, organizations and networks to take similar actions.

Where taking action is dependent on other partners or decision-makers, we commit to continuing to collaborate and engage in dialogue with them to advocate for change to improve the lives of Ontarians with a progressive life limiting illness. We will also continue to build the case for change from wherever we sit in the system.



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

This is a complex, system change initiative. The *Declaration of Partnership* presents a vision of the future state that we aspire to create – one that could be applied as a population based approach for Ontario’s health system, beyond a focus on advanced chronic disease and palliative care. Acknowledging that the evolution to a more integrated population-based system is complex, we understand that improvements will be iterative. However, we as a partnership are committed individually and collectively to moving forward immediately with a targeted focus that puts us on the path to achieving a more integrated future state.

We have agreed that we will work first to advance the following shared priorities:

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p><b>TAKE ACTION NOW</b> All partners agree to take action consistent with the <i>Declaration of Partnership</i> within their respective scope of influence and control in order to advance high quality, high value palliative care in Ontario</p> <p>All partners will share the <i>Declaration of Partnership and Commitment to Action</i> with their respective organizations, associations, etc.</p> <p>All partners to develop workplans or processes to carry out their action commitments</p>	<p>By January 2012, the Ministry of Health and Long-Term Care (MOHLTC) will report to the Minister of Health and Long-Term Care (minister) about this process</p> <p>By January 2012, Local Health Integration Networks (LHINs) will present the <i>Commitment to Action</i> to all LHIN Chief Executive Officers (CEOs)</p> <p>Through winter 2011/12, MOHLTC, LHINs, the Quality Hospice Palliative Care Coalition, and OACCAC re ICCP will develop implementation guides; public materials; and organize next steps for broader engagement., including working with relevant associations and partners</p>
<p>All partners agree to pursue the model of care endorsed through this engagement as one of the foundations for broader health system transformation, and not as a one-off, specialized model unique to palliative care.</p>	<p>MOHLTC and LHINs to consider in the context of a strategic dialogue on health system transformation, including models for shared accountability that may be applicable to other priority policy areas.</p>
<p><b>KEY ISSUE: BROADEN ACCESS AND INCREASE TIMELINESS OF ACCESS</b></p>	
<p><b>ENSURE EARLY IDENTIFICATION AND ACCESS TO SUPPORTS AND CARE OPTIONS</b> Implement proposed “Child &amp; Adult Hospice Palliative Care – Chronic Disease Continuum Model”.</p> <p>Develop and implement additional and complementary mechanisms at the front line to help individuals with advanced life limiting illness identify symptoms that could be managed through appropriate pain and symptom management and other palliative care services, including episodic support.</p>	<p>MOHLTC is supporting the uptake of the chronic disease continuum model as well as the integration of palliative care with chronic disease health care through an agreement with the Ontario College of Family Physicians (OCFP). This includes:</p> <ul style="list-style-type: none"> <li>• Disseminating knowledge of best practices, promoting uptake, and linking sectors and services through common practice, processes, structures and education</li> </ul> <p>QHPCCO will expand provincial representation to include chronic disease associations (i.e., CHF, COPD, Dementia, Diabetes, Stroke, Renal, Lung etc.,)</p>

<sup>8</sup> Note: The order of the Action Commitments does not reflect the sequencing of the actions. They are organized according to theme (“Key Issue”). Sequencing will need to be considered by the change agents as they develop their workplans.

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
	<p>In developing their regional palliative care program/networks, LHINs will focus on integrating with advanced chronic disease management (CDM) and will include representatives from CDM sectors/services not typically identified as palliative</p> <p>The Integrated Client Care Project is expanding the timeframe for palliative services to the last year of life. Identification includes people living with chronic diseases as per the CCAC's new population based service models where palliative is a sub-population of both chronic and complex groupings.</p>
<p><b>ENHANCE NAVIGATION AND CARE COORDINATION TO INCREASE ACCESS</b>  Following diagnosis of a life limiting illness, introduce a dedicated navigator to follow the individual throughout their disease process and ensure seamlessness across the necessary health care settings, initially targeting individuals with advanced chronic disease</p> <p>Promote awareness and cultural shift related to palliative care – encourage individuals diagnosed with a chronic disease to adopt a system navigator to promote knowledge and quality throughout the palliative care journey</p>	<p>Ontario Association of Community Care Access Centres (OACCAC) and Community Care Access Centres (CCACs) to build into on-going implementation of their Client Care Model.</p> <p>LHINs to engage CCACs or other Health Service Providers (HSPs) to implement through optimizing existing resources, building on learning from evidence-guided models as well as the Integrated Client Care Project (enhancements are including navigation with many services outside the traditional CCAC or health systems, i.e. social determinants of health, coping, etc.)</p> <p>MOHLTC to consider in the context of on-going policy development</p>
<p><b>MORE EQUITABLE ACCESS FOR ALL POPULATION GROUPS</b></p> <p><i>First Nations</i></p> <p>Leverage learning and knowledge from research (e.g. "Developing End of Life Care in First Nations Communities" (a toolkit of evidence informed community based strategies to develop local palliative care programs in First Nations communities, funded by CIHR))</p>	<p>MOHLTC to consider in the context of on-going policy development</p> <p>Researchers will make the findings of the referenced work available to the MOHLTC and the Chiefs of Ontario via the Canadian Virtual Hospice website and other appropriate venues (January 2012 onwards)</p> <p>The Health Director of Six Nations will work with the Chiefs of Ontario to</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>Ensure that people living in First Nations communities have access to culturally sensitive and appropriate palliative care services at home on reserve.</p> <p>Ensure that Aboriginal people living in urban areas have access to culturally sensitive and appropriate palliative care services.</p> <p><i>Marginalized Populations</i></p> <p>Require that correctional institutions work with palliative experts to ensure that incarcerated individuals have access to palliative care</p> <p>Develop ways of identifying people in each community who could benefit from palliative services but are not currently identified as in need (e.g. those with chronic illnesses, homeless populations, residents of LTCHs etc.)</p> <p>Ensure resources are available to health care providers to enable them to provide interpreter services when needed for the individual and family (i.e., print material, electronic or phone access, etc.).</p> <p>Consider key findings and implications arising from research concerning the palliative care needs of people living with disabilities (e.g. from VP-NET research) and develop new ways to improve access, delivery and support options to this population.</p>	<p>advocate with the Ontario MOHLTC and the federal government to address the jurisdictional issues that contribute to lack of palliative care service.</p> <p>LHINs will ask their Aboriginal Health Leads to develop a coordinated plan to address this gap in service at the regional level.</p> <p>MOHLTC will seek opportunities to raise awareness of the issue with federal and provincial ministries responsible for correctional services.</p> <p>LHINs via their Regional Networks/Programs will develop a plan to identify people who are chronically ill or otherwise marginalized and would benefit from palliative care services but are currently not receiving access. As part of this plan, LHINs will engage the appropriate stakeholders (e.g. this could include the Quality End of Life Care Coalition of Canada, VP-NET researchers, various associations, etc.)</p> <p>As part of this process, LHINs will consider population needs as well as rural and urban characteristics and initiate planning discussions with HSPs in all care settings</p>
<p><b>MORE EQUITABLE ACCESS ACROSS GEOGRAPHIES</b></p> <p><i>Rural and Remote Communities</i></p> <p>Develop and implement a provincial model of rural palliative care based on best practices specific to the realities of rural and remote areas to ensure that people living in rural and remote communities have access to appropriate care services that enable them to remain</p>	<p>MOHLTC to consider in the context of on-going policy development</p> <p>Hospice Palliative Care Ontario (HPCO) will initiate a dialog with hospices on expanding the volunteer's scope of practice in response to increasing pressure from rural communities for volunteers to do more. At the April 2012 provincial conference, HPCO will host an open space event for</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>in their communities and in their own homes.</p> <ul style="list-style-type: none"> <li>• Leverage learning and knowledge from research and other best practice initiatives that have created models for developing and sustaining local palliative care teams in rural communities (e.g. review "Timely access and seamless transitions in rural palliative/end of life care", Niagara-West "Shared Care" teams, etc.)</li> <li>• Leverage technology (e.g. Ontario Telemedicine Network (OTN) and others) to improve access to palliative care in rural and remote communities.</li> </ul>	<p>visiting hospice services to examine scope of practice for volunteers and determine how the scope may be widened.</p> <p>LHINs via their Regional Networks/Programs, working collaboratively with HSPs and other local rural health and social service providers in rural and remote communities, will develop an integrated regional plan and model to deliver community rural palliative care building upon local resources.</p> <p>Rural palliative care researchers will synthesize best practices from their work and the literature to inform LHIN planning.</p> <p>LHINs, via their Regional Networks/Programs, to engage OTN about opportunities to leverage its technology to improve access to Telehomecare, remote consultation and other strategies, leveraging learnings through ICCP.</p> <p>HPCO will work with MOHLTC, Ontario College of Nurses, RNAO and Registrar General's office to have the Expected Death in the Home protocol fully implemented (this will allow a nurse to certify death and expedite removal of the body from the home).</p>
<p><b>CREATE EFFECTIVE PLANNING AND MEASUREMENT TOOLS TO ENSURE NEEDS-BASED RESOURCE ALLOCATION AND OPTIMAL UTILIZATION</b></p> <ul style="list-style-type: none"> <li>• Develop population-based capacity and resource utilization benchmarks and ensure equitable distribution of resources.</li> <li>• Measure service utilization to ensure that most people receive on-going care and support through primary or blended primary/secondary teams, and that direct delivery specialist level services are reserved for the small percentage of individuals with highly complex needs</li> </ul> <p>(Note: For Paediatrics, specialists may act in a primary role).</p>	<p>In the context of an overarching palliative care data strategy, MOHLTC and LHINs, working with Health Quality Ontario (HQP) and other experts, will consider palliative population-based and resource utilization benchmarks, including jurisdictional, regional and organizational comparisons. This will include leveraging work completed as part of the Integrated Client Care Project.</p> <p>LHINs via their Regional Networks/Programs will seek opportunities to implement agreed upon benchmarks through their normal planning processes.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>In order to develop appropriate benchmarks, further explore and clarify the expectations of different care settings (e.g. Complex Continuing Care, Long-Term Care Homes, hospitals (acute, rehab and tertiary), Residential Hospices, and an individuals' home – private residence, retirement home, group homes, shelters and any setting where individuals live and die) in relation to an integrated continuum of care options in Ontario based on strong value principles</p>	
<p><b>KEY ISSUE: STRENGTHEN CAREGIVER SUPPORTS</b></p>	
<p><b>BUILD CLIENT AND CAREGIVER EMPOWERMENT AND CAPACITY</b>            Develop a “caregiver declaration of rights” and embed it in HSP service plans to clarify expectations and accountability for all partners to support informal caregiving.</p> <p>Develop a “client declaration of rights” to embed in HSP service plans and build on existing legislative rights.</p> <p>Sectors / HSPs should include the person and their family and designates in developing the goals of care and overall care plan and organizing the team (to the extent the person wishes).</p> <p>Encourage the use of client and family care conferences with the inter-professional care team to discuss or update goals of care, disease prognosis, advance care planning, and to provide overall information and offer support.</p> <p>Palliative programs will adopt self-management as a core philosophy where appropriate; individual choices and independence are respected.</p> <p>Build definition and dialogue on palliative care definition into existing caregiver education programs, university and college programs and patient and family education material (e.g. to improve understanding of individuals, families, care providers and society on palliative care versus end of life with the predicted outcome of earlier willingness to be identified as</p>	<p>QHPCCO will develop a “caregiver declaration of rights”. Development will include a review of existing “carer” or “caregiver” bills (legislation) or declarations (policy) of rights within Ontario as well as nationally and across other jurisdictions.</p> <p>QHPCCO will develop a “client declaration of rights” that builds on existing legislative rights. As part of this work, QHPCCO will review the Canadian Hospice Palliative Care Association (CHPCA) Patient/Client Bill of Rights and solicit feedback from LHINs via their Regional Networks/Programs.</p> <p>Following completion, QHPCCO will work with its members, and LHINs will work with their HSPs, to embed the declaration of rights into their service plans.</p> <p>MOHLTC and LHINs will seek direction to publicly engage individuals and caregivers more broadly to further inform policy directions and expand on actions.</p> <p>The Integrated Client Care Project is using experienced based design to ensure that service for any one client/patient and family/caregivers are built upon individual needs and preferences.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>a benefiting from palliative supports)</p> <p><b>MORE FLEXIBLE BENEFITS</b>            Educate individuals and families about the Compassionate Care benefit when appropriate (e.g. end of life phase).</p> <p>Based on current evidence and knowledge about caregiver support requirements, leverage and strengthen policy related to formal and informal unpaid support systems. For example, advocate for the extension of the Compassionate Care Benefits from 6 weeks to what is being suggested by the CHPCA where opportunities arise (e.g. through Health Accord with respect to existing provincial and federal caregiver benefits).</p> <p>Liaise with corporate and business sectors to promote the value in ensuring employees have access to appropriate caregiver support benefits</p>	<p>MOHLTC will seek opportunities to raise issues with other provinces / territories and with the federal government in regards to federal programs and funding to support caregivers.</p> <p>QHPCCO and MOHLTC will examine the recommendations of the federal parliamentary committee on palliative and compassionate care with respect to improving caregiver benefits</p> <p>QHPCCO will liaise with CHPCA and private and public business leaders to promote corporate awareness (for example, through Ontario Chambers of Commerce, and business-led initiatives such as GlaxoSmithKlein )</p> <p>QHPCCO will gather workplace policies from across Ontario (all sectors) that support employees to take compassionate leave and will identify and publicly acknowledge best and leading practices.</p>
<p><b>IMPROVE ACCESS TO SERVICES</b>  <i>Bereavement</i>            Access to grief and bereavement support is core to palliative care delivery. LHINs and HSPs should ensure bereavement support is available appropriately (based on need) prior to and after the death of a loved one</p>	<p>LHINs and HSPs to review program mandates and seek opportunities to expand availability of bereavement service. LHINs to clarify the expectation that HSPs should proactively follow up with family members after a client's death to identify whether bereavement support is required.</p> <p>The Integrated Client Care Project has defined bereavement services as an integral part of palliative care.</p>
<p><i>After Hours Support</i>            Require care teams to provide individuals and their family members with clear information and a designated point of contact when questions or issues arise after normal business hours to ensure the Emergency Department is not the default (note: the point of contact could vary according to the individual's needs, the care setting, and might also change over time).</p>	<p>LHINs to clarify the expectation for 24/7 responsiveness in accountability agreements with all HSPs.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p><b>INFORMATION TO SUPPORT CAREGIVERS</b> Identify caregiver needs in different contexts (community, long term care, rural, dementia care etc.) and develop a simple pamphlet and supporting toolkit for caregivers that raises awareness and provides guidance.</p> <p>Strengthen and leverage existing on-the ground supports for informal caregivers (including financial, skill building, social networking, mentorship, and web-based supports)</p>	<p>QHPCCO to centrally coordinate common information guides and develop a common toolkit that would be available provincially and adopted by all regions and available to all sectors. Include supports resulting from this work as part of the “Central Hub” – see public awareness actions below</p> <p>LHINs via their Regional Networks/Programs will build on the common toolkit by supplementing and maintaining information that is specific to their region (e.g. available programs, etc.)</p> <p>LHINs via their Regional Networks/Programs will examine ways to strengthen and leverage existing on-the ground supports for informal caregivers.</p>
<p><b>MEASURE THE EXPERIENCE OF INDIVIDUALS AND CAREGIVERS AND ENGAGE THEM IN SYSTEM PLANNING AND EVALUATION TO CONTINUALLY IMPROVE EXPERIENCE</b> Explore the use of a standardized tool or objective proxies to measure individual and caregiver experience based on the entire episode of care; including continuity across different care settings (i.e. that is not isolated to experience within unique sectors).</p> <p>Explore how the system can report regularly on experience as part of the proposed balanced scorecard approach.</p>	<p>Beginning in 2012, the MOHLTC and LHINs, working with Health Quality Ontario (HQO) and other experts, will consider a process to collect experience data in the context of an overall palliative care data strategy. This will include leveraging work completed as part of the Integrated Client Care Project.</p>
<b>KEY ISSUE: STRENGTHEN SERVICE CAPACITY AND HUMAN CAPITAL IN ALL CARE SETTINGS</b>	
<p><b>STRENGTHEN PRIMARY DELIVERY THROUGH ACCESS TO SECONDARY AND TERTIARY LEVEL EXPERTISE</b> Ensure primary and secondary providers in each community have timely and appropriate access to specialized palliative expertise (e.g. inter-professional palliative consult teams available to all care settings as well as other processes (for education, mentorship and specialized consultation))</p> <ul style="list-style-type: none"> <li>• Provide expert palliative (when it is needed) through an inter-professional team approach that includes skilled palliative care service providers becoming a part of the</li> </ul>	<p>MOHLTC to consider in context of policy development</p> <p>LHINs via their Regional Networks/Programs will examine ways to strengthen and leverage access to palliative care expertise at all levels (primary, secondary, tertiary).</p> <p>QHPCCO to synthesize available literature and evidence-based consultation team models, any identified population guidelines, funding</p>



SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>core team of primary providers</p> <ul style="list-style-type: none"> <li>• Determine what resources are needed within each community to ensure access to palliative consult team(s)</li> <li>• Avoid duplication of consultation level services in any one region</li> </ul>	<p>formulas, etc and provide information to LHINs via their Regional Networks/Programs for planning considerations.</p> <p>LHINs via their Regional Networks/Programs will complete a gap analysis of what currently exists within each LHIN area in order to determine what resources can be leveraged or what new resources may be required.</p>
<p><b>CONSISTENT AND STANDARD<sup>9</sup> EDUCATION AND COMPETENCY REQUIREMENTS FOR ALL LEVELS OF CARE PROVISION (PRIMARY, SECONDARY, AND TERTIARY) ACROSS CARE SETTINGS</b></p> <p>Operationalize the three “Provider Roles in Hospice Palliative Care” (e.g. <u>primary, secondary, and tertiary</u>) (CHPCA model to guide hospice palliative care):</p> <p>Involve professional colleges in the development of palliative care education at all levels and implement palliative care core competencies as part of the basic training curriculum for health professionals (includes regulated and non-regulated professionals working in palliative care)</p> <p>Base educational training on the “Domains of Issues Associated with illness and Bereavement” (CHPCA, 2002).</p> <p>Deliver clear communication targeted at new and existing Health Human Resources and HSPs to ensure these palliative care competencies are met.</p> <p>Ensure education targets individuals who are going to be in a position to put the skills into practice (building champions).</p> <p>Research and knowledge translation should be considered an Inter-professional Practice</p>	<p>QHPCCO, working in collaboration with the Palliative Care Consultants Network and the relevant associations will gather competency documents related to palliative care for all professional disciplines.</p> <ul style="list-style-type: none"> <li>• Identify palliative care competencies for each discipline (regulated and non-regulated) at each level (primary, secondary, tertiary).</li> <li>• Provide a snapshot survey of current competencies of palliative care providers in all care settings to determine baseline.</li> <li>• Include a scan of competencies being developed through research (e.g. Lakehead University work on PSW palliative care competencies in LTCHs)</li> <li>• Identify gaps.</li> </ul> <p>Based on the above, MOHLTC, LHINs, and QHPCCO will seek opportunities to raise awareness of issues and gaps with the Ministry of Training, Colleges and Universities (MTCU) and professional colleges in order to strengthen palliative care core competencies as part of training curriculum.</p> <p>The QHPCCO and the Palliative Care Consultants Network will:</p> <ul style="list-style-type: none"> <li>• Provide education aimed at the three streams (primary, secondary and tertiary), to support continuing education needs and teach the identified</li> </ul>

<sup>9</sup> For the purposes of this document, standardized delivery, education or tools means that common core elements will be consistently available provincially, while respecting and promoting the need for local flexibility and adaptation through implementation.

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>standard.</p> <p><i>Primary Care:</i> Incorporate palliative into core services across the primary health care system including Family Health Teams (FHTs), Community Health Centres (CHCs), etc. Education and support chronic disease programs to integrate palliative care early in the illness trajectory.</p> <p><i>Nurse Practitioners (NPs):</i> Consider innovative ways to optimize the role of NPs in the system, and in particular to maximize the impact of the new palliative care NP investments from the MOHLTC in terms of accelerating system change (e.g. consider ways to train NPs in palliative care competencies through coaching and mentoring models that leverage the skill and expertise of the Palliative Pain and Symptom Management Consultants).</p> <p><i>Personal Support Workers (PSWs):</i> Identify core competencies for PSW's in alignment with other inter-professional team members to strengthen the role and recognition of PSWs as a critical team member. HSP training activities should highlight the role of PSW and its value to the client experience versus just "task-oriented" care delivery.</p>	<p>competencies.</p> <ul style="list-style-type: none"> <li>• Ensure their representative sitting on the Canadian Nurses Association (CNA), College of Nurses of Ontario (CNO) and Registered Nurses' Association of Ontario (RNAO) advisory committees are aware of the practice issues related to education and practice requirements at each tier.</li> </ul> <p>LHINs to clarify expectations that HSPs ensure their employees receive appropriate ongoing education and skill training</p> <p>Ontario College of Family Physicians (OCFP) to engage the Ontario Medical Association (OMA) and regional medical societies on providing education on new OCFP endorsed standards of practice.</p>
<p><b><u>Volunteers</u></b></p> <p>Ensure that all non-hospice volunteers have appropriate and specific palliative training.</p> <p>Identify gaps where training may not exist and commission the development of the related curricula.</p>	<p>QHPCCO will work with HPCO to identify gaps where training may not exist and also leverage existing volunteer competencies and education programs (e.g. training or certification programs)</p>
<p><b>COMPREHENSIVE CURRICULUM</b></p>	<p>See above - MOHLTC, LHINs, and QHPCCO will seek opportunities to raise awareness of issues and gaps with MTCU and professional colleges</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>Ensure that curriculum includes:</p> <ul style="list-style-type: none"> <li>- Social science based practice</li> <li>- Knowledge exchange on cultural norms</li> <li>- A relational based diversity approach</li> <li>- A focus on grief and bereavement care at all levels, but addressed at the primary level as fundamental care pre- and post-death (encourage an evidence based health and wellness model for families and teams e.g. mindfulness meditation for non-pharmacy pain management, stress reduction, managing depression/ anxiety/self-regulation and enhancing resiliency - see work of Dr Richard Davidson, Dr Dan Segel)</li> <li>- The integration of Chronic Disease Management into each level of palliative care provider role (primary, secondary, tertiary) and vice versa</li> <li>- Education scaffolding for each of the three levels (requirements in core curriculum (students) as well as opportunities for ongoing interdisciplinary education (existing HHR))</li> <li>- Self management strategies (caregiver and client / patient education needs) including symptom management and advanced care planning</li> <li>- Different / adapted education models based on cultural needs and that take into account the intergenerational considerations of cultural values</li> </ul> <p><i>EVOLVING AND EVIDENCE BASED CURRICULUM</i> Curriculum is informed by research and knowledge translation, through education institutions and the evaluation of practice including social science based practices.</p>	<p>in order to strengthen palliative care core competencies as part of training curriculum.</p>
<p><b>SKILL AND EXPERTISE IN COACHING, MENTORSHIP AND SPECIALIZED SUPPORT TO BUILD AND SUSTAIN PALLIATIVE CARE COMPETENCIES AS WELL AS EXPERTISE</b></p> <ul style="list-style-type: none"> <li>• Identify coaching and mentoring roles required at each level of care provision (primary, secondary, and tertiary)</li> <li>• Develop competencies for coaching/mentoring</li> <li>• Include mentoring and coaching skills as part of the competencies at each level of</li> </ul>	<p>QHPCCO to develop a work plan to survey existing information on mentoring and coaching strategies</p> <p>LHINs via their Regional Networks/Programs will complete a gap analysis of what currently exists within each LHIN area in order to determine what resources can be leveraged as well as recommendations for capacity building and improvements</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>education / training and care provision</p> <ul style="list-style-type: none"> <li>• Establish an expectation that providers need to access coaches and mentors</li> <li>• Establish a mentoring / coaching program in each inter-professional team in the community</li> <li>• Provide education on coaching strategies (especially to secondary and tertiary experts) such as 'knowledge to action'</li> <li>• Introduce funding models to incent individuals to provide coaching and mentoring</li> </ul>	
<p><b>CENTRAL HUB THAT PROVIDES HANDS ON COACHING, MENTORSHIP AND SPECIALIZED SUPPORT TO BUILD AND SUSTAIN PALLIATIVE CARE COMPETENCIES AS WELL AS PROVIDE EXPERTISE WHERE IT IS NEEDED</b></p> <p>Create a Central Hub for care providers to provide support in the delivery of the three levels of competency at the local level. The Hub will:</p> <ul style="list-style-type: none"> <li>- Provide a single source of expert advice and information that is accessible in multiple ways (internet, social networking, email, telecommunications, outreach, etc.)</li> <li>- Include a central registry of palliative care mentors for all levels of care providers (primary, secondary and tertiary)</li> <li>- Introduce regular sessions and small group solution-based learning as well as other multi modal approaches (e.g. telecommunications, social media, etc.) to enhance knowledge transfer / knowledge exchange / knowledge to action across care providers.</li> </ul> <p>Ensure it is a safe place for sharing and for enquiries</p>	<p>MOHLTC, LHINs and QHPCCO, working collaboratively, to consider options and seek opportunities to develop a “central information hub”, including consideration of what existing resources can be leveraged</p>
<p><b>PHYSICIAN ENGAGEMENT</b></p> <p>Ensure the right financial incentives and delivery supports are in place to broaden and optimize physician engagement in palliative care across the continuum</p> <ul style="list-style-type: none"> <li>• Improve uptake of palliative care billing codes (including APP funding, etc.) and applications for facilitated access</li> <li>• Explore innovations in billing with respect to consultation and shared care support in palliative care units and other care settings</li> </ul>	<p>OCFP, in collaboration with MOHTLC, LHINs, to seek opportunities to enhance physician engagement (including through the Integrated Client Care Project, LHIN palliative care leads and OMA negotiations)</p> <p>All Integrated Client Care Project palliative sites have engaged physician leaders to build/strengthen the relationships among family physicians, palliative specialists, community outreach teams, community nurses and case managers.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
	<p>OCFP (with MOHLTCH and OMA) to review palliative care billing codes (including paediatricians) for barriers, opportunities for innovation, education opportunities and to optimize best use of resources.</p> <p>OCFP will ensure family physicians are aware of existing billing codes.</p>
<p><b>OPTIMIZE RESIDENTIAL HOSPICES TO SUPPORT INDIVIDUALS WHO CANNOT BE CARED FOR AT HOME BUT WHO DO NOT REQUIRE CARE IN A HOSPITAL</b></p> <p>Ensure Ontario residents have equitable access to this resource, where care in this setting is the most appropriate and cost effective based on individual and family preferences and level of need</p> <p>Establish an appropriate level of consistency across regions</p> <p>Review client population (e.g. profile and needs) and care delivery models within existing free-standing residential hospices to understand any existing variations (delivery and cost and outcomes)</p> <p>Explore establishing formal accountability relationships with LHINs</p> <p>Consider innovative approaches to reduce capital costs (e.g. using existing spaces, expanded volunteer practice, etc.)</p>	<p>HPCO and PEOLCN in collaboration with MOHLTC, LHINS, to launch a residential hospice action group to further explore issues (including policy and delivery) and develop a business case for change</p> <p>HPCO has convened a rural residential hospice working group to look at alternate models of care for residential hospice in rural settings. The group is to report back in January 2012.</p>
<p><b>STRENGTHEN AND OPTIMIZE PALLIATIVE CARE DELIVERY IN LONG-TERM CARE HOMES (LTCHs)</b></p> <p>Focus LTCH improvement activities on enhancing the palliative care experience for residents and their families</p> <ul style="list-style-type: none"> <li>Identify current challenges and improvement activities / opportunities in LTCHs to enable effective delivery of palliative care</li> </ul>	<p>Relevant associations (OLTCA, OANHSS, Ontario Long Term Care Physicians) in collaboration with PEOLCN, MOHLTC and LHINs, to launch an action group to discuss how the hospice philosophy and approach to care may be implemented in LTCHs and to further explore issues (including policy and delivery) and develop a business case for change.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<ul style="list-style-type: none"> <li>• Complete a gap analysis of the resources (e.g. access to specialty palliative care physicians, consult teams, etc.) and supports required to deliver palliative care in LTCHs</li> <li>• Prioritize resources, training, mentorship to support effective pain and symptom management</li> <li>• Review regulations and compliance in LTCH to ensure they enable a shift to the new palliative care model, including transitioning from using Levels of Care forms as plans of treatment to a process that complies with legislation</li> <li>• Consider the redevelopment of LEAP for LTCH</li> <li>• Ensure integration with other care settings where LTCH residents require care outside the facility (e.g. residential hospice, palliative care in-patient bed, etc.).</li> </ul> <p>Leverage learning and knowledge from existing research to inform clinical, operational, policy, educational &amp; community engagement interventions (for example SSHRC funded research, "Quality Palliative Care in Long Term Care Alliance")</p> <p>Ontario Long-Term Care Association (OLTCA) and the Ontario Association of Non-Profit Homes &amp; Services for Seniors (OANHSS) to develop &amp; deliver education based on "Quality Palliative Care in Long Term Care Alliance" (toolkit of evidence informed clinical, policy, educational &amp; community engagement interventions)</p> <p>Ensure "Centre of Excellence" models for LTCH include a research, delivery, and training focus on optimizing pain and symptom management and comfort measures</p>	
<p><b>STRENGTHEN AND OPTIMIZE PALLIATIVE CARE DELIVERY IN HOSPITALS</b></p> <p>Ensure a high functioning and well integrated palliative care strategy that fully considers the role of hospitals (acute, complex continuing care and other) in the provision of palliative care (and acknowledges how different hospitals play different roles in the provision of palliative care supports).</p>	<p>Ontario Hospital Association (OHA) and member hospitals, in collaboration with PEOLCN, MOHLTC and LHINs, will establish an action group to further explore issues (including policy and delivery) and develop a business case for change.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>Enable hospitals to work collaboratively with other stakeholders in an effort to provide greater clarity as to the role of different hospitals and help drive quality improvement.</p> <p>Enable hospitals to share their knowledge and best practices and be a partner in advancing any system changes required to the delivery of palliative care along the continuum.</p> <p>Determine a baseline of existing palliative care delivery models and the typical patient profile / needs in different hospital settings (e.g. acute, rehab, complex continuing care)</p> <p>Establish or have access to ethics committees or ethics consultation across care settings in order to address ethical conflicts at the end of life for both children and adults and inter-professional teams.</p>	<p>The Integrated Client Care Project is engaging hospitals as essential partners to collaborate on the use of specific hospital palliative resources, but also to avoid emergency room visits and unexpected hospitalizations whenever possible.</p> <p>LHINs via their Regional Networks/Programs and HSPs will ensure that hospitals are engaged as partners in integrated delivery processes and mechanisms</p>
<b>KEY ISSUE: IMPROVE INTEGRATION AND CONTINUITY ACROSS CARE SETTINGS</b>	
<p><b>INTEGRATED DELIVERY THROUGH TEAMS</b></p> <p>Provide care through an inter-professional care team approach. Teams will be fluid in their members as defined by individual / family need throughout the illness journey and inclusive of palliative care specialists (e.g. including palliative consult teams) when appropriate.</p> <ul style="list-style-type: none"> <li>• The person and family are at the centre of the care.</li> <li>• Providers in each care setting are part of a “virtual team” that spans all the care settings and sectors through which the person may pass</li> <li>• The team ensures that psychosocial and spiritual supports are a core component of the team approach.</li> <li>• Professional members of the care team make referrals to volunteer services and acknowledge that informal care providers and volunteers are an integral part of the team (as directed by the person and family).</li> <li>• Ensure that the overall care plan follows the person throughout their disease trajectory and is communicated through all settings, seamlessly for person and family.</li> </ul>	<p>MOHLTC policy statements should endorse care delivery through the use of integrated team approaches</p> <p>LHINs, QHPCCO and relevant associations will leverage learning from the Integrated Client Care Project and/or other evidence-guided models to build strong teams through functional realignment</p> <p>The Integrated Client Care Project is testing local integration and shared accountability with the understanding that the ‘team’ for any one client/patient and family/caregivers is individually constituted based on the needs and preferences of the client, and will often include providers from outside the traditional CCAC and health care sector.</p> <p>MOHLTC review existing programs that do not have LHIN-based</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<ul style="list-style-type: none"> <li>• The overall care plan is developed collaboratively between providers, client and family (to ensure it is woven around the individual needs of the person and family).</li> <li>• Care in any care setting and by any set of providers is part of an overall care plan, ensuring timely information sharing within and across all care settings and providers, e.g. community pharmacies, home care providers, community support services, hospitals, Complex Continuing Care, LTCH, retirement homes etc.</li> <li>• Include value-based, advanced care directives (e.g. not treatment and or decision making alone) as part of the common care plan that are reflective of the individual's wishes and are updated as circumstances evolve.</li> <li>• Identify common elements that should be standard in the care plans of individuals receiving palliative care specialty services.</li> </ul>	<p>boundaries (e.g. pain and symptom management consultants).</p> <p>LHINs will begin to implement the vision through service planning with Regional Networks/Programs and HSPs. LHINs will include an expectation in agreements with HSPs that integrated care include palliative care philosophies and supports where necessary, and early on in the trajectory of disease. This will include establishing expectations for standardized delivery across all care settings within a region / community in order to effectively implement the integrated team-based approach. Expectations will be included in HSP accountability agreements</p>
<p><b>COMMON PROCESSES AND PRACTICES SHOULD BE DEVELOPED AND STANDARDIZED WHERE APPROPRIATE ACROSS ALL SETTINGS</b></p> <p>Develop common processes and practices in the most appropriate format, where required.</p> <ul style="list-style-type: none"> <li>• Identify standardized evidence-based screening tools, assessment tools and guides to practice that are applicable and can be linked across all LHINs, care settings, and levels of care for all life limiting diagnoses / chronic diseases (this may involve the adaptation and adoption of current best practice tools (e.g. Palliative Performance Scale etc)).</li> <li>• Agree on which standard elements to implement for screening, assessment, and guides to practice that align with best practices and the Palliative Care – Chronic Disease Continuum model.</li> <li>• Streamline referrals to palliative care settings (e.g. residential hospices and palliative care units, etc.) across LHINs and, where possible, across the province.</li> </ul> <p>Use evidence guided palliative care practice standards as part of Chronic Disease management in all care settings.</p>	<p>MOHLTC policy statements should endorse common processes and practices</p> <p>The Integrated Client Care Project will align with the OCFP best practice work. In the meantime the Integrated Client Care Project is using the CHPCA standards and is developing expectations of what must be consistent across the province.</p> <p>LHINs via their Regional Networks/Programs will clarify expectations for standardized delivery across all care settings within a region / community in order to effectively implement the integrated team-based approach to care. This will include working with researchers and HSPs to assess what work is required and address any gaps and barriers or common issues in order to implement linked screening, assessment and care-planning tools in all care settings, using shared technology as an enabler...</p> <p>QHPCCO and relevant associations will work with members to promote the adoption of evidence based best practices.</p>



SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p><b>USE INNOVATIVE TECHNOLOGIES AS AN ENABLER OF INTEGRATED DELIVERY</b> Leverage technology solutions that currently exist as enablers for integration and coordination. Evaluate solutions for client centredness including ease of spread and expandability, ensuring that these are linked with eHealth strategies to develop interface between systems. For example, identify technology enablers to support the transmission of a common overall client care plan across providers engaged in client's care.</p>	<p>MOHLTC and LHINs to consider in the context of broader e-health strategies</p> <p>LHINs, QHPCCO and relevant associations will leverage learning from the Integrated Client Care Project and/or other evidence-guided models.</p> <p>The Integrated Client Care Project will reimburse CCAC contracted providers in a fashion designed to stimulate experimentation with innovation, including technology.</p>
<b>KEY ISSUE: STRENGTHEN ACCOUNTABILITY AND INTRODUCE MECHANISMS FOR SHARED ACCOUNTABILITY</b>	
<p><b>CLINICAL LEVEL CROSS-SECTOR ACCOUNTABILITY</b></p> <p><b>Clinical level- Implement a mechanism to ensure accountability for provider performance (related to palliative care and advanced chronic disease) in each care setting where people die. This mechanism will clearly articulate and implement the following assumptions and expectations:</b></p> <ul style="list-style-type: none"> <li>● Clarify the accountability of all HSPs to integrate their delivery and function effectively as part of an extended virtual team - care in any care setting and by any set of providers is part of an overall care plan (see integration section above)</li> <li>● Standardized performance monitoring and outcome tracking at the client/team level will occur through a clearly defined process.</li> <li>● Each member of the team is directly accountable to the person receiving care and the team for their contribution towards achieving the care plan goals.</li> <li>● Team monitors and responds to person and family experience data or other standardized quality indicators</li> <li>● Publicly funded providers share accountability for improving population and system performance outcomes</li> <li>● Clinical programs demonstrate implementation of best practices that are aligned with local, regional and provincial priorities and objectives.</li> </ul>	<p>LHINs to enact through their accountability agreement with each HSP</p> <p>LHINs via their Regional Network/Programs to develop a standard template to codify the shared accountability of team members working in extended inter-professional teams to each other; and in relation to their contribution to common client and team goals</p> <p>QHPCCO and relevant associations to work with members to build capacity and readiness to implement (this process will include engagement with HSPs (CCAC / community service provider agencies, Hospices, Hospitals (acute care, tertiary and complex continuing care), LTCHs, Palliative Consult Teams, primary care and other providers as locally relevant))</p> <p>MOHLTC and LHINs, working with Health Quality Ontario (HQO) and other experts, will consider performance indicators and data collection mechanisms in the context of an overall palliative care data strategy.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<ul style="list-style-type: none"> <li>• Create mechanisms for team members to be accountable to each other (for example, through shared, transparent mutual performance reporting , standard of tiered mediation and conflict resolution)</li> </ul>	<p>This will include leveraging work completed as part of the Integrated Client Care Project.</p> <p>The Integrated Client Care Project is testing the development of shared assessment, shared care plans and shared accountability among all of the providers for any one client/patient.</p>
<p><b>ORGANIZATIONAL LEVEL CROSS-SECTOR ACCOUNTABILITY</b></p> <p><b>Organizational level – Implement a mechanism to ensure organizational accountability/governance so that palliative care is provided (as needed) in each care setting where people die and that organizational resources are able to participate collaboratively and effectively in cross sector/cross service teams.</b></p> <p><i>Clarify accountability of organizations to add value (i.e. track outcomes relative to cost and strengthen performance and reporting relationships)</i></p> <ul style="list-style-type: none"> <li>• Each organization is responsible for performance monitoring, including person and family experience, and outcome tracking as it relates to hospice palliative care provided within that care setting</li> <li>• Organizations’ performance systems will be aligned with local, regional and provincial regional priorities and demonstrated in accountability agreements and Health Quality Ontario reporting requirements</li> </ul> <p><i>Create mechanisms for organizations to be accountable to each other</i></p> <ul style="list-style-type: none"> <li>• Each organization is responsible for performance monitoring and outcome tracking as to how that care is integrated within the overall care plan- performance will be benchmarked and transparent</li> <li>• Organizations are accountable for supporting their staff to function effectively as part of extended teams, and to each for meeting performance and quality expectations to achieve the goals of care</li> </ul>	<p>See above</p> <p>In addition, LHINs via their Regional Network/Programs to develop a standard organizational collaboration template to codify organizational accountability to one another (e.g. cross-sector and shared)</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p><b>REGIONAL LEVEL GOVERNANCE</b></p> <p><b>Regional level – LHINs to strengthen or develop a comprehensive integrated Hospice Palliative Program in each LHIN that includes inter-agency accountability (agencies and programs work together) using existing or improved network/program structures that are accountable to and funded by the LHIN and are based on the provincial policy statement.</b></p> <ul style="list-style-type: none"> <li>● Promote key principle of equitable access and opportunity for all Ontarians by supporting a consistent approach to regional palliative care service planning</li> <li>● Strengthen / establish structured regional networks/programs acting in a delegated and/or advisory capacity to the LHINs <ul style="list-style-type: none"> <li>○ Membership would be representative of all palliative care sectors/services (funded and non-funded); sectors/services concerned with advanced chronic disease management but not typically identified as part of the palliative care sector; and including appropriate community members representing people and families,</li> </ul> </li> <li>● The role of the Regional Networks/Programs will include: <ul style="list-style-type: none"> <li>○ Establishing recommendations for a regional plan aligned with the provincial strategy</li> <li>○ Receiving regular reports submitted to LHINs from palliative care agencies, teams, providers as needed to establish evidence of adequate clinical service implementation and quality performance metrics</li> <li>○ Identifying regional service gaps and priorities</li> <li>○ Identifying and recommending needed resources to address priorities</li> <li>○ Identifying and recommending integration opportunities, including opportunities to ensure advanced chronic disease management practices effectively incorporate a palliative care approach</li> <li>○ Advising LHINs as to how agreed levels of funding should flow to appropriately performing elements of the system</li> </ul> </li> </ul>	<p>LHINs to enhance or establish a LHIN - Regional Network/Program task force to initiate action on the identified priorities and proposed next steps. Requires detailed work plan and projections based on achievement of other milestones. Work plan could be based on Champlain program steps and other successful models. Networks/Programs once enhanced will be able to lead this and numerous other processes.</p> <p>Initiate immediately after engagement strategy and fully implement 1-3 years after Engagement Strategy Report.</p> <p>LHINs via their Regional Networks/Programs to develop integrated regional palliative care service delivery plans and outcomes. LHINs to identify palliative care as a regional inter and intra agency priority and to mandate minimum (integrated) standards for palliative care in all settings.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<ul style="list-style-type: none"> <li>○ Implementing consistent mandate for Regional Networks/Programs in each LHIN to strengthen equity across LHINs</li> <li>○ Advising the LHINs in development, implementation and oversight of accountability agreements with all key sectors and organizations currently delivering palliative care services to the targeted client group with the expectation of a meaningful response.</li> <li>○ Providing advice and recommendations to the LHINs on new programs, initiatives and funding proposals to ensure that they are implemented in an integrated fashion so as to reduce duplication and fill gaps to ensure person and family experience is one of seamless access to and continuity of an overall agreed plan of care, striving for creative ways to support families.</li> </ul> <ul style="list-style-type: none"> <li>● Adequate, consistently funded leadership of all Regional Networks/Programs</li> <li>● Continue to oversee and monitor the performance of the Regional Network/Program to ensure it operates in an efficient, effective manner, streamlines delivery and adds value to the LHINs and Ontarians, does not create unnecessary additional administrative burdens or layers, through application of LEAN principles and processes where appropriate.</li> </ul> <p>Establish clear, consistent and transparent accountability relationships between MOHLTC, LHIN and Regional Networks/Programs and fund holding agencies (HSPs)</p> <p>LHINs with Regional Networks/Programs to promote integration strategies within accountability agreements with each health service provider such that collaboration occurs at all levels of planning and service delivery</p> <ul style="list-style-type: none"> <li>● For example, develop and establish palliative care policy/advisory statements which will articulate that all care settings caring for dying individuals will offer palliative care programming and will report on this programming. In addition these policy/advisory statements will facilitate effective <u>integration</u></li> <li>● Develop inter and intra agency accountability structure on the regional level</li> </ul>	

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p><b>PROVINCIAL LEVEL POLICY GUIDANCE AND DIRECTION</b></p> <p>Provincial - Strengthen provincial policy and accountability:</p> <ul style="list-style-type: none"> <li>• Establish provincial palliative care policy statement or service plan which supports a consistent approach to regional palliative care service planning</li> <li>• Embed effective accountability measures, for LHINs relating to palliative care delivery, in existing Ministry-LHIN Accountability Agreements (MLPAs),</li> <li>• Establish clear policy, legislative, and regulatory frameworks for excellent, best practice palliative care delivery</li> <li>• Use funding levers to ensure equitable funding to create the right incentives and payment mechanisms to shift sectors towards outcome-based payment models where practical and appropriate</li> <li>• Review funding plans for physician services</li> </ul> <p>Provincial - Establish a centralized process to ensure ongoing oversight of the palliative care system in Ontario. This may be a newly created role or a revision of the mandate of an existing process to include broader palliative care oversight (e.g. ER ALC process, LHIN Collaborative (LHINC) etc.)</p>	<p>MOHLTC will consider and seek direction in relation to ongoing policy development that ensures equitable access to high quality palliative care services for the people of Ontario</p>
<p><i>Strengthen accreditation and academic research</i></p> <p>Promote involvement of palliative care services/programs in voluntary, (provincial / national / international) standardized accreditation/evaluation processes.</p> <p>Promote enhanced provincial funding opportunities for academic research specializing in palliative care</p>	<p>QHPCCO (including PEOLCN and HPCO) will request opportunity to work with Accreditation Canada, Commission on Accreditation of Rehabilitation Facilities (CARF), etc. to include palliative care standards within the standard statements of each care setting where individuals die.</p> <p>QHPCCO (including PEOLCN and HPCO) will identify appropriate existing accreditation options for various settings to consider as voluntary participants (i.e. listing accrediting programs and their target agencies).</p> <p>MOHLTC will identify research opportunities to inform policy guidance and direction.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p><b>MEASURE SYSTEM PERFORMANCE FROM THE PERSPECTIVE OF CLIENTS AND CAREGIVERS</b></p> <p>Create provincial system level performance measures, targets</p> <ul style="list-style-type: none"> <li>● Establish a strong mandate for consumer defined system performance using indicators that measure: <ul style="list-style-type: none"> <li>○ quality of life, and quality of dying/death, system responsiveness and person-centred care evaluation</li> <li>○ integration from the client/family/caregiver perspective, and;</li> <li>○ outcomes, system impact, provider engagement, experience and sustainability</li> </ul> </li> <li>● Leverage work to date (e.g. Integrated Client Care Project, Cancer Care Ontario, etc) on performance metrics</li> <li>● Recommend the implementation of metrics that will drive ongoing improvements in integrated, team-based delivery structures and processes and ensure that recommended metrics are evidence-based</li> <li>● Develop scorecard and processes for public reporting</li> <li>● Develop checklists for HSPs as a way to monitor process, qualitative, and quantitative outcomes on an ongoing basis to inform continuous quality improvement</li> <li>● All actions should have longitudinal evaluations ongoing to reflect ability to analyze and synthesize new knowledge and tools for a continuous quality improvement methodology.</li> <li>● Include a process to refresh metrics on an annual basis depending on state of evidence and knowledge</li> <li>● Ensure that all organizations providing palliative care meet the quality and reporting expectations of the <i>Excellent Care for All Act</i></li> </ul> <p>Conduct system-level evaluation, monitoring and reporting on education improvements. Translate outcomes into comprehensive system level evaluation, monitoring and reporting.</p>	<p>Regional Networks/Programs and HSPs should seek research funding opportunities for palliative care.</p> <p>MOHLTC and LHINs, working with Health Quality Ontario (HQO) and other experts, will consider a process to develop recommendations for performance indicators, measurement and reporting and performance corridors or benchmarks, and experience data in the context of an overall palliative care data strategy. This will include leveraging work completed as part of the Integrated Client Care Project.</p> <p>LHINs via their Regional Networks/Programs and QHPCCO will consider a process for development of supporting resources / toolkits to support continuous quality improvement.</p> <p>LHINs and HSPs to review accountability agreements to include accountability for monitoring integration and palliative care performance.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>Ensure final products assist LHINs and HSPs to establish expectations for performance (e.g. through clearly defined outcomes) that are appropriate and measurable as a way to ensure organizations are delivering appropriate care and to enable providers to continuously improve.</p>	
<p><i>Support evaluation and impact assessment</i></p> <ul style="list-style-type: none"> <li>• Evaluate existing innovations</li> <li>• Include client and/or family perspective as part of system evaluations of processes and care delivery (e.g. include perspective of individuals and caregivers with respect to providers' comfort in discussing palliative care, etc.)</li> </ul>	<p>MOHLTC has provided funding to ICES to commission a rigorous impact assessment as part of Integrated Client Care Project.</p> <p>See actions above - review of experience measures to be considered as part of palliative data strategy.</p>
<p><b>KEY ISSUE: BUILD PUBLIC AWARENESS</b></p>	
<p><b>BUILD PUBLIC AWARENESS AND ENGAGE IN PUBLIC DIALOGUE</b></p> <p>Develop, fund and implement a Public Awareness campaign (using “Speak Up” tailored to Ontario) to increase the general public’s understanding of palliative care and its broader role in chronic disease management.</p> <p>Include advanced care planning as part of campaign:</p> <ul style="list-style-type: none"> <li>• Ontarians should be aware that advanced care planning happens early-on after receiving a life-limiting diagnosis.</li> <li>• Develop a consistent, transferable and seamless mechanism for advance care planning to be communicated, to ensure the continuation and elaboration of the conversations throughout the disease journey across in all care settings and that is accessible to all care providers.</li> </ul> <p>Initiate a campaign (linked to above) to encourage open discussions about end of life and earlier referrals to palliative care</p> <ul style="list-style-type: none"> <li>• Develop communication and relational strategies/ tools to assist health care providers in “truth telling” to individuals and families that are respectful of their beliefs, values</li> </ul>	<p>MOHLTC, LHINs and QHPCCO, working collaboratively, to explore options and seek opportunities for increasing general public’s understanding and awareness (including capitalizing on existing work to date)</p> <p>OCFP clinical expert care pathing committee to work with HSPs, including providers from various chronic disease specialties, to improve competency related to open discussions with individuals around palliative care.</p>

SHARED PRIORITIES AND PROPOSED NEXT STEPS	ACTION COMMITMENTS <sup>8</sup>
<p>and culture (e.g. training on relationship based models (MM) as well as tools to assist providers in explaining a disease trajectory, etc.).</p> <ul style="list-style-type: none"> <li>• Educate individuals and their families on the models of care and community supports that will be / are available.</li> <li>• Ensure individuals and their families know that they will have access to palliative care teams, residential hospices, CCC and/or palliative care beds when / if it ever becomes required.</li> <li>• Ensure individuals and their families are aware that, in each care setting where someone dies, they will have access to skilled palliative care providers.</li> </ul>	
<p><b>IMPROVE ACCESS TO INFORMATION - CENTRAL HUB FOR INFORMATION AND SUPPORT</b></p> <p>Create a single source of expert advice and information that is accessible in multiple ways (internet, social networking, email, telecommunications, outreach, navCare, etc.)</p> <p>Ensure it is a safe place for sharing and for enquiries</p> <p>Include information that is customized for different groups.</p> <p>Develop a peer mentorship program for the public.</p>	<p>MOHLTC, LHINs and QHPCCO, working collaboratively, to consider options and seek opportunities to develop a “central information hub”, including consideration of what existing resources can be leveraged</p>



## Appendix A: Definitions

**Accountability** – a relationship based on obligations to demonstrate, review, and take responsibility for performance, both the results achieved in light of agreed expectations and the means used.<sup>10</sup>

### **Advanced Chronic Disease**

Adults or children with an active, progressive life-limiting illness where the disease has advanced to the extent that clinicians and others would not be surprised if the person were to die within 12 months. Clinical evidence supports that the disease is advanced (for example, presence of medical conditions associated with advanced disease, severe and progressive symptoms, rapid decline, or decreased functional status). Some examples of advanced disease include:

- extensive metastatic disease in cancer
- refractory cardiac failure
- total dependency in neurodegenerative conditions
- multi-organ system failure (e.g. end-stage renal disease)
- advanced heart and/or lung disease (e.g. chronic obstructive pulmonary disease or chronic heart failure)
- advanced genetic, metabolic or other congenital or acquired conditions which are predicted to shorten their life (usually death is possible or probable by the mid twenties)
- severe frailty and/or dementia, especially with first occurrence of medical complications
- older adults at risk of requiring or in long-term care who have multiple co morbidities and/or extensive polypharmacy especially who experience significant decline

EOL Chronic Disease refers to those Individuals as above were the probability of death is imminent.

It is noted that individuals with these above conditions are at high risk of exacerbations that might require multiple hospitalizations. With proper disease management and palliative care, some of the risk can be mitigated and avoided, preventing unnecessary acute care utilization.

### **Caregivers:**

Formal caregivers are members of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers or volunteers. They are sometimes called “providers.”

Informal caregivers “are not members of an organization. They have no formal training and are not accountable to standards of conduct or practice. They may be family

---

<sup>10</sup> Report of the Auditor General of Canada to the House of Commons Chapter 9 Modernizing Accountability in the Public Sector pg. 1 Accessed at <http://www.oag-bvg.gc.ca/internet/docs/20021209ce.pdf>

members or friends or other people in the client's/patient's network who are partners in providing care and personal support.”<sup>11</sup>

### **Hospice palliative care**<sup>12</sup>

A philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement
- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Individuals with palliative care needs are those where a strong (but not necessarily exclusive) focus of care is the relief and prevention of suffering and improving quality of life and comfort.

### **HPC/EOL Care Networks:**

End of life care networks are local collaboratives of HPC organizations and caregivers with a formal mandate to utilize their collective expertise to work together to promote high quality integrated hospice palliative care in their regions. The Networks are proactive with each adjusting their organizations to meet local needs and now include newly established regional programs. The Network Leaders come together to form the Provincial EOL Care Network. Their mandate is consistent across the province and their accountability rests with their corresponding LHIN.

### **Hospice Volunteer**

Individuals who volunteer with a Visiting Hospice Service or Residential Hospice and who have received formal training based on the standardized curriculum of Hospice Palliative Care Ontario.

**Integration and 'integrated care'**<sup>13</sup> – describe a dynamic set of methods and models on the funding, administrative, organizational, service delivery, and clinical levels to produce connectivity, alignment, collaboration and coordination within and between the cure and care sectors for complex, multi-problem patients/clients whose needs cut across multiple services, providers and settings in order to achieve the following outcomes:

- Improved patient/client experience and satisfaction
- Enhanced quality of care, quality of life, and health-related outcomes
- Greater system/service efficiency, effectiveness and value.

---

<sup>11</sup> HPCO Residential Hospice Standard

<sup>12</sup> (CHPCA) Model to Guide Hospice Palliative Care (2002)

<sup>13</sup> Source: Kodner,2009: Kodner & Spreeuwenberg, 2002 (ICCP definition)

### **ICCP Integrated Client Care Project**

A collaboration among LHINs, CCACs, their contracted service providers, and all other palliative care providers in the local area. Executive sponsors are the MOHLTC, LHINs, Collaborative for Health Sector Strategy at the Rotman School of Business, and Ontario Association of CCACs. At locales in the Southwest, Toronto Central, Waterloo Wellington, Central West and Hamilton Niagara Haldimand Brant LHIN areas.

**Inter-professional Team** – is the provision of comprehensive services to individuals by multiple caregivers, who work collaboratively to deliver quality care within and across settings. It is a collaborative, team-based approach to providing optimal care. The goal is to achieve regular and frequent dialogue between all caregivers, within and between settings as necessary. As part of inter-professional care, all caregivers (including unregistered staff, volunteers and families) see themselves as part of the individuals care team. (Interprofessional Care: A Blueprint for Action in Ontario).

It is noted that an inter-professional team may include and subsume other dedicated or formally organized teams available in some care settings. For example, the HPCO Residential Hospice Standard is for an Interdisciplinary Care Team, which is defined as a team of caregivers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers and volunteers. Other disciplines may be part of the team if resources permit.

### **Levels of Care Provision (Canadian Hospice Palliative Care Association)**

- **Primary providers**
  - Manage disease, its manifestations and the predicaments it creates
  - Identify issues
  - Provide the core competencies of palliative care
  - Have enough basic level palliative care awareness that they can identify individuals requiring palliative care and manage this care
  - Access appropriate palliative care specialists as required to effectively support their client's needs, goals and preferences
  - Primary providers include all providers in any sector who offer first level or first response contact with individuals in relation to their health, including physicians and their assistants, nurses and nurse practitioners, personal support workers and home-makers, allied health professionals, etc
  - Within the group of primary providers, there will be a most responsible provider identified to manage the client's overall care plan
- **Secondary Experts**
  - Are experts in palliative care
  - Support primary providers in every setting where individuals/families receive care
  - Identify individuals requiring tertiary level palliative care and refer them appropriately
- **Tertiary Experts**
  - Consult to secondary experts and primary providers on difficult-to-manage cases

- Educate/train secondary and tertiary experts
- Conduct research
- Develop advocacy strategies

**Progressive Life-Limiting Illness** – is a term used to describe illnesses where it is expected that death will be a direct or secondary consequence of the specified illness. In the context of this report, this term includes all phases of disease progression, from diagnosis to death.

### **Residential Hospice**

A community based inpatient facility with a primary focus of providing hospice palliative care to individuals facing end-of-life and operating in compliance with HPCO Community Residential Standard. Not a hospital, long-term care home, or retirement home.

### **Shared Care**

- Shared-care is a model of care and although “shared-care” can have different meanings, in this document its definitional use is in the broadest sense, where care is “shared” amongst different combinations of multidisciplinary professionals (regulated and unregulated), in different capacities, working in different types of teams, in different funding models, and within and across care settings.
  - It includes primary care providers and does not replace primary care providers with specialist level providers
  - It is not limited to relationships between primary care providers and specialist level providers.
  - It is not limited to care shared between providers of the same profession.
- Ultimately however, all “shared-care” teams or integrated HPC delivery models aim to achieve care that is coordinated, proactive, holistic, person and family-focused, centering on quality of life and symptom management issues.

**System Navigator** – A process which involves assessment, collaborative identification of needs and goals, coordination, and linking to services and resources within and beyond the health service sector which support efforts to achieve optimal health or functioning, independence and psychosocial wellbeing.

### **Visiting Hospice Service<sup>14</sup>**

A support service where trained volunteers matched with service recipients and supervised to provide practical, emotional, social and spiritual support to those who are living with a life-threatening or terminal illness and their families

---

<sup>14</sup> Adapted from OHRS 8.0 and HPCO

## **Appendix B: What Success will Look like and Roadmap for Broader Health System Transformation**

The model articulated in this paper is generic and can be adapted to health care delivery for all Ontarians with chronic disease. Over the next 10 years, Ontarians should expect a health care system that is patient-centred, achieves better outcomes and is more cost effective.

Adults and children with chronic disease and their informal caregivers should expect to have access to comprehensive, integrated, personalized health care, community and social services that respond to their needs, goals and personal circumstances. They will have the right supports to remain in their communities, have their chronic disease managed optimally and relieve the burden on informal caregivers. This will reduce pressures on hospitals and long-term care homes, ensuring that the health care system will be there for future generations.

Ontario will achieve this vision by shifting from fractured, sector-based delivery to a redesigned, “person-centric” system focused on chronic disease and health promotion/prevention based on three fundamental principles:

1. Individuals and caregivers will be supported to navigate and direct their own care.
2. All providers across all care settings and across time will work together as members of a team to achieve common goals.
  - a. The team will be constructed around the individual/family needs, rather than requiring the individual to fit into existing programs.
  - b. Team members may transition in and out of the team as they are needed around the individual.
3. Each team member will be supported to use best practices to achieve quality outcomes and their results will be evaluated against measurable criteria, e.g. improved outcomes, cost effectiveness.

At the delivery level, adults and children and their informal caregivers will receive care and supports that are proactive, holistic and person and family-focused provided by a virtual, extended inter-professional team.

At the regional level, primary providers will have access to specialized resources and supports that are organized through a formal program or network structure to build capacity and support high quality delivery. Regional programs also provide planning and funding advice to LHINs to improve the equity, effectiveness and consistency of the care and supports available across the region. Examples of regional programs might include:

- Regional Integrated Hospice Palliative Program
- Regional Geriatric Program
- Behavioural Support Ontario
- Cancer Care Ontario etc

# Roadmap for Health System Transformation

## *Access*

- Use simple information to build awareness
- Each community or care setting dedicates a care coordinator to oversee the set up and optimal functioning of team-based delivery (initially focused on sustained, on-going care coordination/complex care management targeted to individuals with advanced or EOL chronic disease or complex palliative care needs)
- An overall care plan guides who will be involved in the team, and what their roles and responsibilities are. It is jointly created by the client/family, the most responsible care provider, and the care coordinator.
- Advance care planning is an essential component of care plan development and will be revisited each time the care plan is updated.
- Over time, each community and care setting establishes coordinated and defined points of access for intake to team-based care. There is a standardized process for screening (case finding) and comprehensive holistic assessment

## *Integrated Delivery (Extended Inter-professional Teams)*

- For clients with advanced chronic disease, the episode of care is considered from point of identification or entry to the system, through death and post-death bereavement. A team will remain with the adult or child and their family through the entire episode of care, providing continuity of care.
- The team works in a collaborative, evidence-based, preventative, proactive care plan with continuously updated assessment, planning, treatment, and monitoring and is supported by excellent communication practices
- A single health record is shared by the team
- Specialist or other providers may transition in and out of the team for the time their resource and expertise is required to achieve specific goals or until their responsibilities are transferred to another provider. Information and results achieved by any provider in any care setting belongs to the client and is retained by the team as part of the client record (including for example, where the client is admitted and discharged from hospital or specialist care during the episode of care).

## *Accountability*

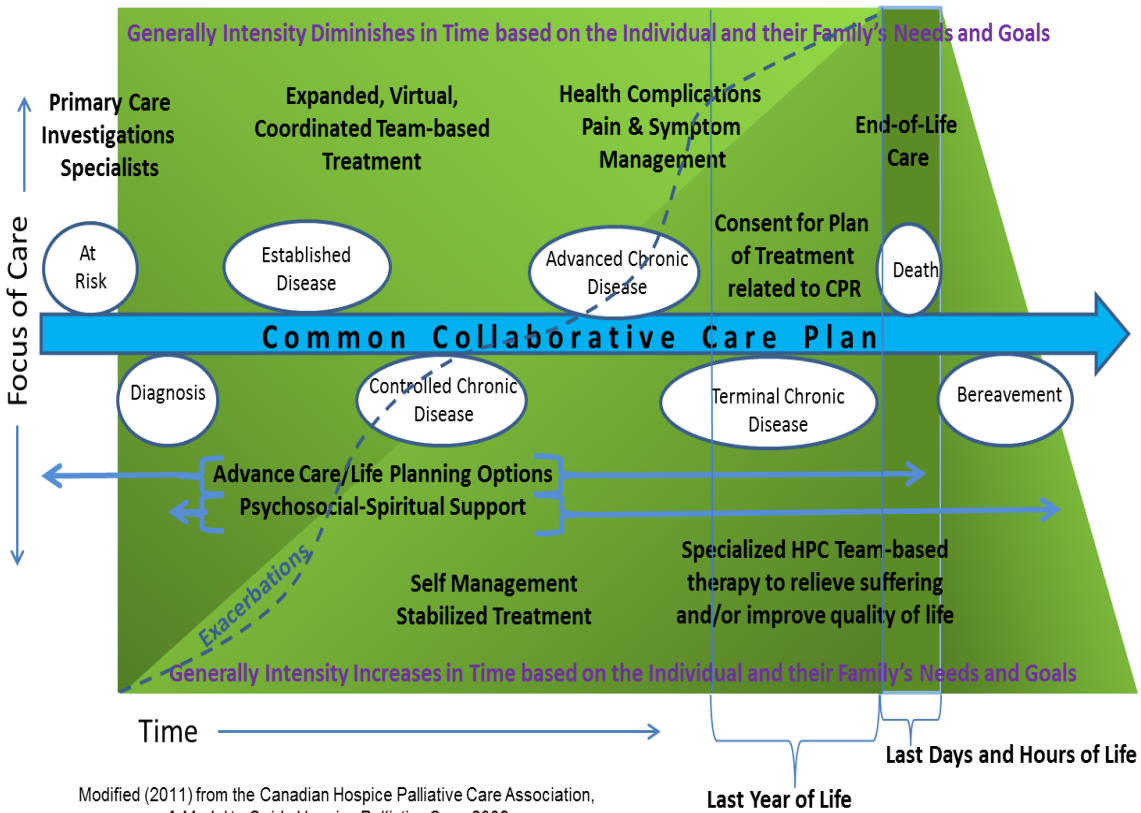
- Clear performance expectations are developed, and the contributions of each team member is measured, and is transparent to other team members

## *System Integration*

- Networks/partnerships mobilize and coordinate a response at the local and regional level and ensure minimum standards are met
- System and regional level policy and planning specific to advanced chronic disease and palliative care delivery, with consistency across regions

It is widely recognized that individuals with Chronic Disease could benefit from a hospice palliative care approach. A model for integrating Hospice Palliative Care into the Chronic Disease Continuum has been developed by the Care Path across the Chronic Disease Care Continuum working group.

## CHILD & ADULT HOSPICE PALLIATIVE CARE - CHRONIC DISEASE CONTINUUM MODEL



The end result for Canadians is a health care system that is:

- **High Quality:** every Canadian will receive care that is informed by evidence and is focused on best outcomes
- **Sustainable:** a health care system that ensures future generations will receive public health care by measuring and continuously improving outcomes and value
- **Accessible:** every Canadian has access to a health care provider in a timely fashion, regardless of their geographic location, health, or social and economic status
- **Continuous:** care received at one point in time from a given provider is coordinated with the care received from other providers and on other occasions
- **Person-directed:** Individuals and families are involved in developing their care plans to take into account their quality of life goals and personal and cultural preferences

# Appendix C: Environmental scan of the current state in Ontario

## Current Data Overview

Note: process is underway to update to most current ON data, where available

Access:

- Only 10% of all deaths are sudden, however, there are at least 70% of Canadians who do not have access to palliative care (and when there is access, it is not equitable) (Carstairs, 2010)
  - As few as 16-30% of Canadians have some level of access to hospice palliative care (Carstairs, 2010)

*(Note: National data – proxy for Ontario. Moving forward, will use ON data as consistently as possible, as opposed to mixture of national and provincial statistics)*

- Access varies by diagnosis:
  - Even though cancer patients represent 28% of Canadian deaths (Statistics Canada, 2005), they made up 55% of referrals to CCACs for End of Life (EOL) care in the first quarter of fiscal year 2011/12 (OACCAC)
  - Seniors account for 75% of deaths each year (Carstairs, 2010) – many have diseases of the circulatory system (35% of deaths) and of the respiratory system (about 10% of deaths) (Statistics Canada, 2005)
- Increased life expectancy and advances in health mean that populations now live longer, but with increased chronic illness at the end of life (Lynn & Adamson, 2006)
  - Chronic diseases result in high health care service utilization such as emergency department usage and inpatient alternative level of care days (MOHLTC Provincial Health Planning Data Base, 2007/08).
  - Chronic diseases are the leading causes of death in Ontario (Health System Intelligence Project reports, 2007).
  - Approximately one in three Ontarians suffers from a chronic disease (Statistics Canada, 2005).
  - 80% of Ontarians over 45 have at least one chronic disease, and 70% of these have two or more chronic diseases (Statistics Canada, 2005).
  - The prevalence of the majority of chronic diseases in Ontario is on the rise.

Mortality Rates for Chronic Diseases per 100,000 Population in Ontario

Chronic condition	Rates per 100,000
	2004-2005 average
Cancer	198.3
Heart disease	123
Stroke	33.3
Chronic obstructive pulmonary	26.3



disease	
Diabetes	25.4
Hypertension	5.9
Arthritis	2.7
Asthma	0.7
Depression	0.4

Source: Health System Intelligence Project (HSIP) reports, 2007 (Crude rates)

*Limitations: Information is incomplete and a mixture of national and provincial averages. Acknowledge many important limitations – for example, current access challenges with respect to Residential Hospices, access to 24/7 supports, variations by geography, etc.*

Capacity:

- Polls suggest that 70 to 80% of Canadians indicate they would prefer to die at home if supports were available
    - Reality: Two-thirds (67%) of Canadians died in hospital (Statistics Canada, 2007)
- (Note: National data)*

Indicators of capacity challenges:

- In home care in Ontario (CCAC), caregiver distress affects about one in five (22%) palliative care clients (*interRAI, 2007 – 2009 data*)
- According to HAO (2009), in 2007/2008, 345,327 acute care bed days and 95,018 Alternate Level of Care (ALC) bed days were occupied by patients with a palliative care diagnosis

Place of death (as an element of capacity)

- Home Care
  - 26% of CCAC End-of-Life clients (SRC95) were discharged because of death in the hospital (OACCAC, FY 08-09)

Placeholder for update to 10/11 data

- Long-Term Care Homes
  - 2009/10 – 47.3% died in LTCH facility in Ontario vs: Canada 52.2% died in facility (CIHI)
  - 2010/11 – 45.4% died in LTCH facility in Ontario (CIHI)

*(Note preference is not indicated – assumption is that residents go to hospital)*

Placeholder for review of LTCH data

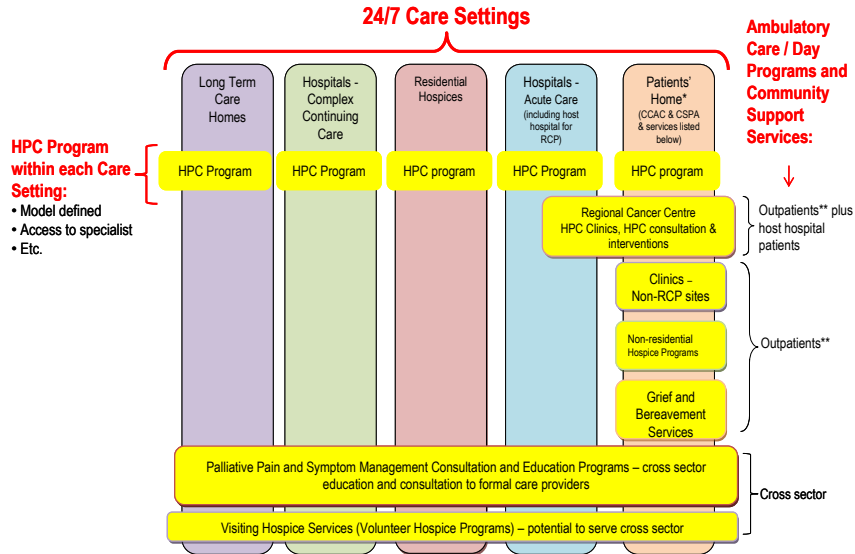
- Hospital deaths
  - In Ontario, for those individuals admitted to hospital with a primary diagnosis of palliative, 6,927 (73%) died in hospital beds (IntelliHealth, MOHLTC, 2008)
    - The average LOS was 13.5 days (2008)

- Total direct costs were \$77.6 M
- The average age of these patients was 72.8 years of age
- 55.5% had two or more admissions before dying in hospital

*Limitations: Does not include all care settings (e.g. Complex Continuing Care, etc).  
Data restricted to primary diagnoses of EOL or Palliative (and therefore incomplete).*

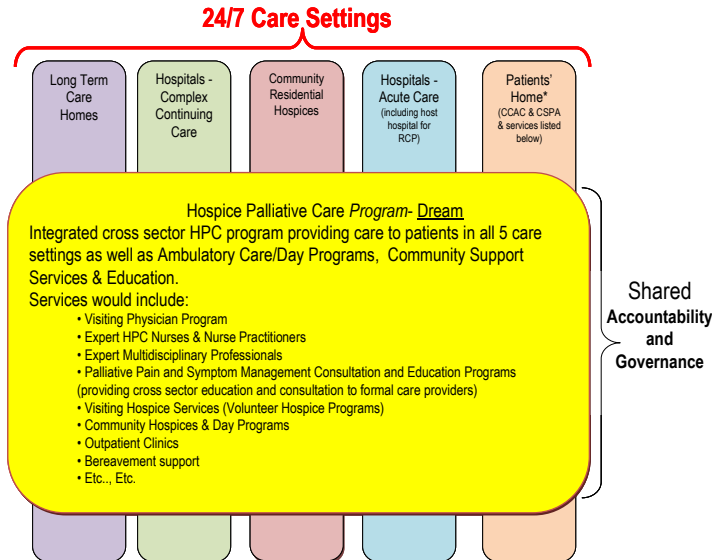
# Gap between the current palliative care delivery system and the desired future state

## Reality HPC "Program" within the "System"



\* "Patient's home" refers to any location where patient is residing (outside of settings included here). This may be a Community Living residence, Group home etc.  
 \*\* "Outpatients" refers to ambulatory & 'transportable' patients & families

## "Dream" Regional HPC Program



\* "Patient's home" refers to any location where patient is residing (outside of settings included here). This may be a Community Living residence, Group home etc.  
 \*\* "Outpatients" refers to ambulatory & 'transportable' patients & families

## System Design Realm One: Care Settings and Services

*Desired Standard: A full continuum of care settings and services is in place as per population based needs*

*Current State:*

Care settings include both private and public care settings including:

- An individual's home (e.g. private residence, retirement homes, Long-Term Care Homes, group homes, homeless shelters, correctional centres, etc.)
- Residential Hospices
- Primary Care
- Hospitals (acute, rehab and complex continuing care)

Currently, key care settings and services that comprise a comprehensive continuum of palliative care supports are lacking in many catchment areas, specifically:

- Residential Hospices
- Tertiary Care Inpatient Units/Services
- Bereavement Services for management of complex grief both before and after the death of a loved one
- Formalized palliative care programs in LTC homes
- First Nations communities

Further, there is currently no clear expectation or role for each care setting in a continuum of palliative care supports. This includes the need to define the role for Residential Hospices and Long Term Care homes and First Nations communities' home and community care programs. Once roles are defined and expectations are set, planners then need to have confidence in their ability to determine the appropriate balance of settings and services in each community across the Province. However, there is currently no evidence-based population guidelines that would assist in this planning and allocation of resources.

Where care settings and services do currently exist, access often remains an issue (for all levels of care including primary, secondary and tertiary).

- Although many programs and services are available, they are variable across the Province which presents issues of inequity (for example, inadequate / inequitable access across the province to integrated, comprehensive, quality pain and symptom management and support).
- Although programs and services may be available, access to them is currently largely determined based on prognosis from a health professional as opposed to being needs based from the perspective of the individual and their family. This is of significant concern given it is often difficult for health professionals to determine a disease prognosis and trajectory and hence there is uncertainty about when palliative services are appropriate. This results in a disproportionate number of referrals being representative of diseases with more predictable prognoses (e.g. cancer). This also results in referrals for less predictable disease trajectories being made closer to the end of life or when death is imminent (e.g. a few weeks or days before death).
- Existing programs and services often act as stand-alone models that are not necessarily integrated amongst each other to care for the complete person and their family.

Limited access also presents concerns over a lack of congruence between the actual locations of death for Ontarians versus their location of choice.

### System Design Realm Two: Programs within Care Settings and Services

*Desired Standard: In each care setting where individuals die there is a clearly defined palliative care program*

#### *Current State:*

Key components of quality palliative care (including comprehensive programs and expertise) are not currently available in many care settings where individuals die. Key components and program elements that are most frequently missing include:

- Adequate palliative care competencies at the front-line in all care settings
- Access to 24/7 palliative care expertise (for both the individual with the Life-Limiting Illness, their family and informal caregivers, and front-line care providers in all care settings)
- Access to an identified palliative care Resource/Lead/Champion/Contact within each care setting to provide education, mentorship and specialized support to primary care providers / front-line
- Clearly defined model of care delivery based on best practice
- Access to inter-professional care within and across care settings
- Key supports for families and caregivers (includes the bereavement phase of palliative care both before and after death)
- First Nations communities lack basic equipment and supplies to provide palliative care at home such as hospital beds, commode chairs, incontinence products, medication and oxygen.

### System Design Realm Three: Integration / Linkages

*Desired Standard: Sectors and services are linked by common practice, processes, structures and education*

#### *Current State:*

Specific integration essentials within each region are lacking or inadequate resulting in fragmentation in care and system inefficiencies as individuals move across care settings or progress through an illness trajectory (poor continuity of care, redundancy of processes, etc.):

- Common clinical practices and processes are lacking across sectors (including use of common tools as well as Advanced Care Planning)
- Shared functional and clinical infrastructures that support cross-sector collaboration are lacking:
  - venues for integrated care planning to develop common collaborative care plans
  - venues for ongoing sharing of information throughout a care plan (e.g. to communicate any changes in care goals, care outcomes, etc.)
  - venues for collaborative process development
  - shared communication / IT with accessible client / patient records between sectors / services

- linked pharmacy databases to prevent medication issues that may compromise chronic disease management
- timely, reliable program and integrated system-level data and analytic capacity to inform decision-making
- Common (and required vs. voluntary) levels of palliative care competencies / education are absent across all sectors and organizations
- There is no true system navigation for individuals and their families
- Lack of integration between existing chronic disease programs and palliative care supports. They are not currently integrated into a continuum of care that spans from diagnosis of a Life-Limiting Illness to Advanced / Terminal Chronic Disease to end of life to bereavement. Instead, individuals are not referred to palliative care supports unless they have an end of life diagnosis.
  - Advanced Care Planning (ACP) does not consistently occur early enough in the disease trajectory
  - Individuals who can provide palliative care are not often a part of the care team early on and in an ongoing nature (e.g. at the point of diagnosis and throughout the disease trajectory to advanced / terminal chronic disease)
  - Lack of integration often results in prolongation of expensive and futile treatments which may neither prolong nor improve life
  - There is a current assumption that access to palliative care is 'binary' (in or out) as opposed to being accessed at varying levels across a disease trajectory
- There is no one point of contact for all individuals / families and care settings on a 24/7 basis
- The transition from pediatric to adult is fragmented (hand-offs across care professionals and teams) and service levels do not remain consistent
- Pharmacy is not well integrated into all care settings and care teams
- Jurisdictional issues between the federal and provincial governments defining responsibility to provide care in First Nations communities creates barriers to high quality care including a lack of funding for service provision and also barriers in the transition of care from hospitals to communities.

#### System Design Realm Four: Human Resources

*Desired Standard: Adequate numbers of trained professionals are available as per population based needs assessment*

#### *Current State:*

Currently, there are no population based guidelines, staffing levels (to help determine / quantify need) or palliative care Human Resource Plan for LHINs or the Province.

Further, given limitations within existing Human Resources, it is challenging to quantify what the need truly is. For example, the number of existing health human resources at all levels of care (primary, secondary and tertiary) with an understanding of, and / or training in palliative care is inadequate as a result of a lack of mandatory palliative care competencies for regulated and non-regulated health professionals. Further, there is also inconsistent levels of support for current human resources (e.g. access to education, mentorship and 24/7 support). As such, it is difficult to understand the need

for additional resources given the need to first understand the potential of existing resources.

Within existing resources, there is a lack of:

- Consistent expectations for all care professionals to engage in Advanced Care Planning when appropriate
- Family physicians that have received culturally relevant palliative care education and are comfortable in caring for palliative individuals who need palliative care
- Primary providers in all care settings that have received culturally relevant palliative care education and are comfortable in caring for palliative individuals who need palliative care in a culturally safe manner.
- Unregulated professionals in all care settings that have received culturally relevant palliative care education and are comfortable in caring for palliative individuals
- Utilizing the full scope of practice of all care providers (e.g. nursing). For example, physicians may often act as the 'gatekeeper' to palliative care through prognostication – there is a need to acknowledge that need can be identified through the individual or family or through needs based assessments completed by other regulated care providers
- Retention within the community (due to variations in pay between the community and institutional sectors)

A lack of access to primary care supports that have adequate understanding and comfort with palliative care may have a number of effects:

- Inappropriate use of specialized supports when individuals could be cared for by primary care professionals.
- Individuals suffering from a Life-Limiting Illness do not have access to palliative care soon enough (providers assume access to palliative care requires a definitive prognosis).

#### System Design Realm Five: Accountability

*Desired Standard: System level accountability is clearly defined and communicated*

#### *Current State:*

Health and social care in Ontario is currently delivered by independent sectors and by independent service providers, each with its own Board of Directors, individual mandate, operational imperatives and strategic directions. Within this multi-sector context, overall shared accountability for the person and family and for the achievement of health system's triple aim goals is currently unclear. There is currently:

- Inadequate accountability, evaluation, monitoring and reporting on outcomes at all levels (provincial, regional and local)
  - No performance standards (all levels)
  - No accountability based on outcomes (all levels).
  - No tracking and reporting on outcomes to drive change (all levels).
- No accountability for the implementation of standardized clinical or system-design best practices required for true integration of care

- No accountability for care providers to partner across care sectors and contribute to one common care plan where individuals require care from multiple care settings
- There is currently no provincial level or regional multi-sector performance measurement. For example, there is often independent monitoring, evaluation and reporting at a program specific and/or facility specific level, however, this has not been rolled up into a system level process or framework.

### System Design Realm Six: Policies, Guidelines and Funding

*Desired Standard: Funding models, guidelines and policy directions support an integrated system*

#### *Current State:*

Variations in the provision of complex and/or advanced chronic disease management and palliative care exist across Local Health Integration Networks (LHIN). Although local flexibility is important, the current level of regional inconsistency creates a provincial landscape in which care and support is piecemeal. Provincial consistency is needed including guidelines and funding models that would drive continuous improvements in service delivery. Examples of current provincial enablers that are required include:

- Provincial performance standards for LHINs and subsequently their health service providers (with recognition of the need for local flexibility in how they are achieved)
  - Including the goal to reduce avoidable expenses (e.g. due to poor care transitions, prolongation of medically futile treatments which may neither prolong nor improve life, unnecessary Emergency Department and inpatient hospital utilization, etc)
- The development and implementation of funding models that incent or support integration and shared care or consultation models (need for innovative models, e.g. in physician billing, etc.)
  - Currently, funding does not follow the client through the care system
  - There is currently poor delineation of and provision of payment mechanisms (e.g., home visiting) including education and training requirements at primary and specialist levels
- Every effort should be made to protect existing palliative care services and resources in all care settings (e.g. protecting current funding for various programs, etc.).

There are also a number of unique issues and gaps that need to be recognized outside of the structural elements of the system that are discussed above. In designing a high quality, high value integrated palliative care system, special attention should be paid to these concerns:

#### Support for families and informal caregivers

Family members and informal caregivers often face increasing burden throughout the disease trajectory of a loved one. In addition to supporting the person, there is a strong need to support their family and informal caregivers who provide the majority of care. This includes the need to improve access to services and supports for informal



caregivers (including access education supports, respite, cultural navigation, system navigation and care coordination, etc.). This also means providing innovative supports. For example, there are currently gaps in supports for single parents as they seek treatment for an ill child but also require child care support for their other (healthy) child(ren).

In order to be responsive to the varying needs of families and caregivers, there is a strong need to hear the voices of individuals living with life-limiting illnesses, their family members and their informal caregivers in system, regional and local level planning and governance.

In addition to supporting those who cope with long disease processes, there is a need to also improve the identification of, and services for, family members of persons who die of sudden illness or events (for example, bereavement services for individuals who experience a suicide-related loss).

### General Public

Palliative care is currently poorly understood by the public and by many service providers resulting in referrals being made too late in the disease trajectory and referrals not being made for individuals with chronic disease / life limiting diagnoses. There is a need to improve public knowledge and expectations of palliative care.

### Responsiveness to all population groups

Our system can not be designed to provide homogenous care. Instead, care must be flexible in order to adequately and consistently respect and respond to the diversity of all Ontarians.

This includes improving responsiveness to culturally/linguistically diverse populations as well as urban/rural/remote populations and First Nations communities (both reserve and urban). It is important to note that language is not the only adaptation to be made (e.g. understanding common terminology, having interpreters available, etc). Providers must also consider and respect the cultural values and beliefs surrounding death and dying.

Understanding that care should be available for all Ontarians, it is important to clearly state the need to better respond to populations that are often marginalized including children (which is a unique sector requiring a specialized skill set of health care providers), individuals living with disabilities, homeless, First Nations, prison populations and individuals with mental health and addictions needs.

In the case of veterans, First Nations and prison populations, roles and responsibilities must be clarified between Federal and Provincial governments. Specific to correctional centres, progress needs to occur to allow natural deaths as opposed to requiring CPR of all inmates. First Nations people must be consulted and First Nations must guide the

development of culturally appropriate palliative care programs and services for their communities.

For individuals living with disabilities:

- An unpredictable path to end-of-life can lead to barrier in accessing palliative care for people with disabilities (e.g. disease trajectory / decline is not typically predictable like cancer might be)
- Chronic poverty/unemployment is more common for those with disabilities which presents challenges in purchasing additional supports if need be (including additional stress)
- Assumptions about living with a disability may influence decision-making at end of life (e.g. physicians, nurses, etc. often assume an individual cannot make decisions about their lives, wishes, etc if they are living with a disability)
- People with disabilities are only seen as care recipients, and not as care providers

### Responsiveness to all geographies

Care must also be flexible in order to adequately and consistently respond to the needs of rural and remote and First Nations communities that are currently struggling with access to adequate levels of palliative care services and supports as well as access to key care settings. More needs to be done to reduce the expectation that individuals travel to seek appropriate care. Travel to urban centres to receive palliative care is costly in time and energy as well as financially. Further, it removes individuals from their homes, communities and informal care supports.

Given recruitment challenges, there is a need to improve competencies within existing resources and to provide innovative technologies to provided access to secondary and tertiary level care.

Rural, remote and First Nations communities have identified a need for support to develop their local primary care palliative care resource teams by dedicated people at the regional level who can work as community catalysts and who have skills in community development. Research has demonstrated the success of this for developing palliative care capacity in rural and First Nations communities.

In addition to reaching remote areas, it is also challenging to reach the multitude of providers within heavily populated urban centres.

## **Appendix D: Workgroup Participants**

(see page 4 for membership of the Leaders Collaborative)

### ***Integration and Shared Care***

Co-Chair - Julie Foley

*Lead, Integrated Client Care Project, Ontario Association of Community Care Access Centres*

Co-Chair - Dr. Mary Lou Kelley

*Professor, School of Social Work & Northern Ontario School of Medicine, Lakehead University*

Co-Chair - Dr. Denise Marshall

*Associate Professor, Division of Palliative Care, Dept of Family Medicine*

*Assistant Dean, Program for Faculty Development, Faculty of Health Sciences, McMaster University*

Writer – Jocelyne Contant

*Executive Director, Champlain Hospice Palliative Care Program*

Writer – Nancy Cooper

*Director of Policy & Professional Development, Ontario Long-Term Care Association*

Editor – Susan Warner

*Project Lead, South West Local Health Integration Network*

Editor – Esther Green

*Provincial Head, Nursing and Psychosocial Oncology, Chief Nursing Officer, Cancer Care Ontario*

Barbara Busing

*Senior Director, Client Services, Hamilton Niagara Haldimand Brant Community Care Access Centre*

Dr. Debbie Harrold

*Palliative Care Physician*

Roberta Lee

*Senior Lead, Health Systems Development, Mississauga Halton Local Health Integration Network*

Belinda Marchese

*Clinical Director, Hospice Toronto*

Dena Maule

*Executive Director, Hospice Toronto*

Ruby Miller

*Director of Health Services, Six Nations Health Services*

Gurjit Sagha

*Clinical nurse specialist, SickKids Palliative and Bereavement Care Service*

Lisa Sullivan

*Lead, Health Services Planning, Champlain Local Health Integration Network*

Jill Tettmann

*Senior Director, Health System Performance, Measurement and Integration, North Simcoe Muskoka Local Health Integration Network*

Nadia Thatcher

*Director of Care , Bethammi Nursing Home*

Sonia Johnson

*Patient Care Manager, Oncology Unit Tower 7 and Palliative Care Unit Tower 6, The Scarborough Hospital General Campus*

## **Accountability and Governance**

Co-Chair - Dr. Nancy Merrow

*Chief of Staff, Southlake Regional Health Centre  
Chair, Central LHIN Palliative Care Network*

Co-Chair - Beth Lambie

Director

*Erie St.Clair End-of-Life Care Network,  
Co-Chair, Provincial End-of-Life Care Network*

Writer / Editor – Georgina White

*Director, Policy and Research  
Ontario Association of Community Care Access Centres*

Writer / Editor – Victoria van Hemert

*Senior Director, Planning, Integration, Community Engagement, Central Local Health Integration Network*

Moderator (DoN) – Penny Anguish

*Vice President, Complex Care & Physical Rehabilitation Services  
Chief Nursing Officer, St. Joseph's Care Group*

Angela Archer

*Director of Care, Malton Village Long-Term Care Home*

Rosslyn Bentley

*Executive Director , Hospice Wellington*

Carol McKenna,

*Clinical Manager, Palliative Care / Chair of Hamilton Niagara Haldimand Brant Hospice  
Palliative Care Network*

*St. Peter's Hospital Site & Adult Acute Sites, Hamilton Health Sciences*

Brenda Carter  
*Regional Vice President, Cancer Services  
Kingston General Hospital and South East Regional Cancer Program  
Chair, South East Palliative and End of Life Care Network Steering Committee*

Dr. Deborah Dudgeon  
*W.Ford Connell Professor of Palliative Care Medicine  
Professor of Medicine and Oncology, Queen's University*

Sherry Frizzell  
*Consultant, Sudbury/Manitoulin, North East Local Health Integration Network*

Betty Kuchta  
*Chief Executive Officer, Erie St. Clair Community Care Access Centre*

Heather Nicolson-Morrison  
*Executive Director, Toronto Central Palliative Care Network*

Dr. José Luis Pereira  
*Full Professor and Head, Division of Palliative Care, University of Ottawa  
Medical Chief, Palliative Medicine, Bruyère Continuing Care / The Ottawa Hospital*

## ***Education, Mentorship and Specialized Support***

Co-Chair - Cathy Joy  
*Palliative Pain and Symptom Management Consultant, Waterloo Region*

Co-Chair - Marg Poling  
*Palliative Pain and Symptom Management Consultant, North West Community Care Access Centre*

Writer – Anne Bell  
*Director Quality and Education Services, Ontario Association of Community Care Access Centres*

Valerie Armstrong  
*Senior Manager Client Services, North Simcoe Muskoka Community Care Access Centre*

Dr. Sandy Buchman  
*Assistant Professor Department of Family and Community Medicine, University of Toronto  
President-Elect, The College of Family Physicians of Canada  
Primary Care Lead Toronto Regional Cancer Program, Cancer Care Ontario  
Education Lead & Family Physician Practising in Palliative Care, The Temmy Latner Centre for Palliative Care*

Elisabeth Catalano-Bon  
*Social Worker, Health Services - Region of Peel, Tall Pines Long-Term Care Home*

Michele Chaban

*Director of Interprofessional Applied Mindfulness Meditation Program, University of Toronto, Dala Lana School of Public Health, Department of Family and Community Medicine, Faculty of Social Work, Center for Bio-ethics*  
*Director of Contemplative End of Life Care Program, The Institute of Traditional Medicine*  
*Faculty liaison, McMaster Applied Mindfulness Meditation Certificate*

Lynn Huizer  
*Senior Manager, Health System Integration, North Simcoe Muskoka Local Health Integration Network*

Dr. Amna Husain  
*Palliative Care Physician, Temmy Latner Centre for Palliative Care, Mount Sinai Hospital*

Donna Ladouceur  
*Senior Director, Client Services, South West Community Care Access Centre*

Dr. Ariella Lang  
*Research Scientist, VON Canada*

Holly Prince  
*Researcher, Lakehead University*

Dr. Adam Rapoport  
*Medical Director of Palliative Care at SickKids and Pediatric consultant to the Temmy Latner Centre*

Kirsten Schmidt  
*Network Coordinator, Central East Local Health Integration Network*

Karen Weisberg  
*Coordinator, Central Hospice Palliative Care Transition Strategy and Engagement*

Pauline Frechette-Keating  
*Manager of Continuing Care, CSR & Infection Control Nurse, Sensenbrenner Hospital*

## ***Care pathing across continuum of Chronic Disease Management***

Co-Chair - Julie Darnay  
*Director, Hamilton Niagara Haldimand Brant Hospice Palliative Care Network*

Co-Chair - Dipti Purbhoo  
*Senior Director, Client Services, Toronto Central Community Care Access Centre*

Writer / Editor – David Fry  
*Director, Client Services, Ontario Association of Community Care Access Centres*

Writer / Editor – Donna Laevens-Van West  
*Executive Director, Central West Palliative Care Network*

Maryse Bouvette  
*Champlain Advanced Practice Nurse, Palliative Care at Bruyere Continuing Care*

Cheryl Faber  
*Senior Manager, Health System Planning and Development, North Simcoe Muskoka Local Health Integration Network*

Catherine Goetz-Perry  
*Planning and Integration Lead, South West Local Health Integration Network*

Lynn Kachuik  
*Palliative Care Advanced Practice Nurse, Ottawa Hospital*

Fran Lind  
*Director of Care , Parkview Home*

Dr. Vincent Maida  
*Palliative Care Physician, William Osler Health System  
Assistant Professor, University of Toronto, Division of Palliative Care  
Clinical Assistant Professor, Michael G. DeGroot School of Medicine, McMaster University*

Sidney Thomson, RN  
*Clinical Education Coordinator, Carleton Place & District Memorial Hospital*

Dr. Andrea Moser  
*Lead Physician, Geriatric Care Team, Algonquin Family Health Team  
Vice President, Ontario Long-Term Care Physicians  
Assistant Professor, Northern Ontario School of Medicine  
Medical Director, Muskoka Landing*

Dr. Jeff Myers  
*Head - Palliative Care Consult Team  
Odette Cancer Centre, Sunnybrook Health Sciences Centre  
Associate Professor and Associate Head - Division of Palliative Care  
Department of Family and Community Medicine, University of Toronto*

Michelle Pauzé  
*Senior Manager, Client Services, North Simcoe Muskoka Community Care Access Centre*

Carol Sloan  
*Manager / Palliative Care Consultant, Palliative Care Consultation Program*

Dr. Patricia Strachan  
*Assistant Professor, School of Nursing, McMaster University*

Dr. Chris Vadeboncoeur, *Pediatric Physician, Children's Hospital of Eastern Ontario*

### ***Project Management Team***

Debra Bell

*Manager, Community Care  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
[debra.bell@ontario.ca](mailto:debra.bell@ontario.ca)  
ph: 416-326-0818*

*Deborah Sattler  
Team Lead, Community Care  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
[deborah.sattler@ontario.ca](mailto:deborah.sattler@ontario.ca)  
ph: 416-326-9266*

*Stephanie Lockert  
Senior Policy Advisor  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
[stephanie.lockert@ontario.ca](mailto:stephanie.lockert@ontario.ca)  
ph: 416-326-6694*

*Diane Allen  
Senior Policy Advisor  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
[diane.allen@ontario.ca](mailto:diane.allen@ontario.ca)  
ph: 416-326-0721*

*Rick Firth  
Executive Director, Hospice Palliative Care Ontario*

*Beth Lambie  
Director, Erie St. Clair End-of-Life Care Network*

*Andrea Martin  
Lead, Waterloo Wellington Hospice Palliative Care  
Co-Chair, Quality Hospice Palliative Care Coalition of Ontario  
Co-Chair, Provincial End-of-Life Care Network*