Ontario Hospice Palliative Care Review
Models, Best Practice Standards, Care Paths and Clinical Practice Guidelines

Collaborative Summit
March 27, 2012
Julie Darnay and Beth Lambie
Background

• This Ontario College of Family Physicians' project was commissioned by the Ministry of Health and Long-Term Care as part of the Advancing High Quality, High Value Palliative Care in Ontario - Declaration of Partnership and Commitment to Action

Project Goal:

• To provide Ontario's health care providers with support to help them plan for and improve the quality of the care that they deliver to persons at the end of life based on the best available evidence
Project Objectives

Section One
• To gather and consolidate current best practice standards, care paths and clinical practice guidelines relevant to establishing a fully integrated hospice palliative care model(s) and delivery system across the continuum of chronic disease management
  – Identify existing gaps, challenges and barriers in terms of achieving a comprehensive inventory of best practice knowledge
  – Flag the highest quality evidence
  – Identify the degree of consensus with respect to application of best practices
  – Assess what further work may be required to address identified gaps and barriers and initiate a sector-led process to develop additional best practices
  – Assess the readiness for uptake of the information and barriers to implementation.

Section Two
• To gather and consolidate existing information and knowledge about current palliative hospice care model(s) in all care settings
  – Assess readiness for the “new model” at the regional level and at the sector specific level
Section One: Julie Darnay

To gather and consolidate current best practice standards, care paths and clinical practice guidelines
Background - Part One

• Health providers need consistent tools to better assess, coordinate and provide quality hospice palliative care to ensure that more chronic disease patients live comfortably and die with dignity in the place of their choice.

• To provide patient-centred care across the many chronic disease illnesses the entire health system needs a better understanding of when, how and where patients should receive hospice palliative care.

• Clinical practice guidelines and pathways are generally an accepted means of promoting quality, consistency, and comprehensiveness across the many domains of hospice palliative care.

• Caution - A Cochrane Collaboration (2009) reported that:
  – Randomized controlled trials are needed for the evaluation of the use of end-of-life care pathways in caring for dying people
  – Further investigations of the effects of such pathways for specific populations are warranted.
Methodology – Part One

• However, it is without a doubt that the consistent adoption of “leading practices” in Ontario will help to establish hospice palliative care as an integral component of the health care of persons living with life limiting chronic illnesses.

• Therefore, a literature search was conducted to identify relevant evidence based best practices, pertinent clinical trials, meta-analysis, systematic reviews, or regulatory statements and other professional guidelines.

• Contributions to the literature review were broadly extended to members of the Ministry’s Care Pathing Working Group, members of the QHPCCO, the 14 Provincial End-of-Life Care Networks, the Provincial Palliative Care Consultants Network, and other disease-based Associations and Specialists.
Methodology – Part One

By Disease
• Including: Cancer, Heart disease/ failure, Respiratory (i.e., Chronic Obstructive Pulmonary Disease – COPD, Cystic Fibrosis etc.), End stage renal, Diabetes, Dementia, Liver, Neurologic (i.e., Stroke, Parkinson’s, ALS – amyotrophic lateral sclerosis, MS – multiple sclerosis), AIDS/HIV , Seriously Compromised Children & Adults (i.e., Developmental Disabilities, Cerebral Palsy), Mental Health, Chronic Disease – General

By Discipline
• Including: Physician, Nursing, Case Management, Pharmacy, Personal Support Worker, Volunteers, Informal Caregivers, Specialized, Support/Interdisciplinary Team

By Care Setting
• Including: Hospital Tertiary, Hospital Acute/Emergency Departments, Hospital Complex Continuing Care (CCC), In Home (Community Care Access Centre [CCAC], Visiting Hospice Services [VHS] & Community Service Provider Agencies [CSPA]), Ambulatory, Residential Hospice, Long Term Care, System (Characteristics, Organization and Roles & Responsibilities

By Population
• Including: Pediatrics, First Nations, Incarcerated Individuals, Needs Of Parents/Siblings Of Adolescents/Young Adults That Commit Suicide Or Die Suddenly Due To Injuries And Illnesses, Vulnerable Populations (i.e., homeless)
DOMAINS OF ISSUES ASSOCIATED WITH ILLNESS AND BEREAVEMENT

Disease Management
- Primary diagnosis, prognosis, evidence
- Secondary diagnosis (e.g., dementia, psychiatric diagnoses, substance use, trauma)
- Co-morbidities (e.g., delirium, seizures, organ failure)
- Adverse events (e.g., side effects, toxicity)
- Allergies

Loss, Grief
- Loss
- Grief (e.g., acute, chronic, anticipatory)
- Bereavement planning
- Mourning

End-of-Life Care/Death Management
- Life closure (e.g., completing business, closing relationships)
- Gift giving
- Legacy creation
- Preparation for expected death
- Anticipation and management of physiological changes in the last hours of life
- Rites, rituals
- Pronouncement, certification
- Peri-death care of family, handling of body
- Funerals, services, celebrations

Physical
- Pain and other symptoms
- Level of consciousness, cognition
- Function, safety, aids (motor, senses, physiologic, sexual)
- Fluids, nutrition
- Wounds
- Habits

Psychological
- Personality, strengths, behaviour, motivation
- Depression, anxiety
- Emotions
- Fears
- Control, dignity, independence
- Conflict, guilt, stress, coping responses
- Self-image, self-esteem

Social
- Cultural values, beliefs, practices
- Relationships, roles with family/friends, community
- Isolation, abandonment, reconciliation
- Safe environment
- Privacy, intimacy
- Routines, recreation, vacation
- Legal issues
- Family/caregiver protection
- Guardianship, custody issues

Person and Family Characteristics
- Demographics
- Culture
- Personal values, beliefs, practices, and strengths
- Developmental stage, education, literacy
- Disabilities

Practical
- Activities of daily living (e.g., personal care, household activities)
- Dependents, pets
- Telephone access, transportation

Ferris et al., 2002

Spiritual
- Meaning, value
- Existential, transpersonal
- Values, beliefs, practices, affiliations
- Spiritual advisors, rites, rituals
- Symbols, icons

Source: A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Canadian Hospice Palliative Care Association (CHPCA). March 2002.
Project Findings - Part One

• The inventory provided a robust framework with which to examine such leading best practices, and develop hypotheses about appropriate and relevant hospice palliative care pathways and tools.

• It also provided an opportunity to discover the areas of both strengths and gaps in the available literature.

• This is a perpetual endeavour and new resources are continually being discovered and added to the framework as they are identified.
Project Findings – Part One

• The inventory identified that there is **no “one size fits all”** model for providing good HPC across all chronic diseases

• While we remain committed to adhering to the Canadian Hospice Palliative Care Association’s (CHPCA) national principles and norms of practice, it was difficult to identify consensus among the vast majority of care providers and organizations across the province regarding the use of consistent approaches to HPC

• While palliative care practices exists across the spectrum of chronic diseases, none matched the sophistication, consistency and potential transferability as the best practice work accomplished within the field of cancer
Project Findings – Part One

• It was noted that the Cancer Care Ontario Palliative Care Strategy in particular offered many opportunities for advancement and expansion since this work embraces a simultaneous approach to care, which can be applicable to other life limiting chronic illnesses

• The CCO Palliative Care Strategy is in accordance with the CHPCA national principles and norms of practice and Accreditation Canada’s standards for hospice, palliative and end-of-life care services

• One of the pillars of the CCO strategy is that each region should have a mix of services that are patient focused, based on the patient’s needs, as opposed to prognosis, and optimizes outcomes for patients

• Since prognostication is often so unpredictable in other chronic diseases this focus of care presents a potential common ground
Project Findings – Part One

• Therefore it was recognized that the CCO strategy and tools (i.e., ESAS and PPS) could be considered an initial starting place for the use of a common set of provincial PC care paths and tools across other chronic diseases.

• A comprehensive management plan that is based on goals of care could therefore include these PC tools in concert with existing disease specific tools to enhance a better understanding and application of when, how and where patients should receive hospice palliative care.

• The second part of this project explored this opportunity through a professional consultation process.
Methodology – Part Two

• An electronic survey was then developed to provide the opportunity for professional input and feedback on the inventory and findings
• The survey contained 30 questions related to this review process
• An initial list of expert chronic disease clinicians from across the province was identified by key stakeholders, networks and associations
• These chronic disease clinicians were then invited to participate and provide their professional input
• In addition, these experts were asked to circulate the survey among other relevant colleagues that would have expertise in this area and who would be interested in participating in the survey.
• One hundred and ninety eight surveys were returned
What is your primary profession?

- Administrator
- Family Physician
- Occupational Therapist
- Physician Specialist (please specify below)
- Physiotherapist
- Registered Nurse (please specify below)
- Researcher/Academic
- Social Worker
- Spiritual Care
- Other (please specify below)
Please list your area(s) of disease expertise in relation to best practice standards, care paths and clinical practice guidelines.
Please list the care setting(s) that you have expertise or experience in relation to best practice standards, care paths and clinical practice guidelines.
Project Findings – Part Two

• The majority of respondents 68% expressed that the inventory framework provided a comprehensive listing of current resources

• In an attempt to move beyond just gathering what is currently available, participants were asked if they agreed that it is now time to look at a fresh system-wide approach to try to integrate palliative care and chronic disease management and to establish some applicable shared best practice care paths.
  – Over 71% of participants strongly agreed
  – Another 26.1% somewhat agreed
Project Findings – Part Two

• Overall there was an extremely high awareness (between 81% - 89%) of the primary best practice hospice palliative care tools including the CHPCA Domains of Issues, the Edmonton Symptom Assessment System (ESAS) and the Palliative Performance Scale (PPS).

• Current use of these tools was also relatively high with between 60% and 70%

• The potential for the extended use of these tools was very positive with 63% to 81% of current users recommending these tools for expanded use across the system of chronic disease management

• Another 33% to 46% of current non-users demonstrated interest in the future use and applicability of these tools.
A number of specific PC best practice standards, care paths, clinical practice guidelines and tools were flagged as providing the highest quality evidence across Chronic Diseases, Care Settings and Stages of Disease Trajectories.

However, it is interesting to note that consistently the ESAS and PPS were acknowledged as best practice tools within:

- 9 of the 11 chronic disease categories
- across all 9 care settings, and
- ranked highest among stages of disease trajectories tools.

Additionally, 7 of the 11 chronic disease categories recognized the RNAO Best Practice Guidelines.
Project Findings – Part Two

• Although there seemed to be a high interest in this practice change process, as suspected there does not seem to be a high degree of overall consensus or agreement with respect to the application of these best practices

• There was evidence of strong pockets of consensus building within the cancer sector (43%), and the AIDS/HIV sector (40%) but this level of agreement was not shared elsewhere across other disease categories

• The Residential Hospices demonstrated the highest consensus building among all care settings with 21%

• Agreement on best practices within stages of disease trajectories:
  – Stable Phase 6.3% indicated a high consensus
  – Transitional Phase 6.3% indicated a high consensus
  – End-of-Life Phase 13.4% indicated a high consensus
Please identify the current degree of provincial consensus with respect to the application of these best practice care paths within the following disease categories.

- Cancer
- Heart disease/failure
- Respiratory
- End stage renal
- Diabetes
- Dementia
- Liver
- Neurologic
- AIDS/HIV
- Severe Compromised
- Children & Adults
- All other responses

Legend:
- Green: Don't Know
- Red: No Consensus
- Purple: Low Consensus
- Blue: Medium Consensus
- Orange: High Consensus
Please identify the current degree of provincial consensus with respect to the application of these best practice care paths within the following care settings.

[Bar chart showing the degree of consensus across different care settings, with green indicating 'Don't Know', red 'No Consensus', purple 'Low Consensus', blue 'Medium Consensus', and orange 'High Consensus'.]
Please identify the current degree of provincial consensus with respect to the application of these best practice care paths within the different stages of disease trajectories.
Project Findings – Part Two

• With respect to system readiness to initiate the changes needed to develop common best practices relevant to establishing a fully integrated hospice palliative care model(s) and delivery system across the continuum of chronic diseases
  – Overall 20% of respondents indicated that the system is very ready to initiate the changes that need to occur
  – Another 60% indicated that the system is somewhat ready to make the necessary changes.
Project Findings – Part Two

• Suggestions on how to support a plan to continue building awareness, engage readiness and disseminate the hospice palliative care best practices across the system
  – Education, mentorship, awareness and engagement of all service providers across the continuum of care
  – The use of the Domains of Issues and concentration on the patient experience, based on the patient’s needs, as opposed to prognosis
  – Inter/Intra-disciplinary and cross sector team based seamless care
  – Primary care engagement to develop and lead the necessary practice change
  – Continued and supported provincial collaboration and consultation of experts across the chronic disease continuum to reach consensus
  – A clear, concise, comprehensive guideline tool kit for physicians and service providers (such as CCO's SMGs)
Recommended Next Steps

Work with an expert clinician panel led by the Quality Hospice Palliative Care Coalition of Ontario and utilize the inventory of resources report and other resources identified in the survey to develop a simplified, easy to use palliative care – chronic disease management tool kit.
Recommended Next Steps

Identify and leverage existing resources available to share information and establish a repository of best practice knowledge gained from the survey to support and strengthen knowledge transfer.

(e.g. Seniors Health Research Transfer Network; other hospice palliative care or health service provider portals used to collaborate and share information; Local Health Integration Network forums).
Recommended Next Steps

Continue to consult, involve and communicate with primary care, front-line clinicians and professional caregivers through local HPC Networks and include them in this broad process and dialogue to obtain their expertise, grow engagement, reach consensus, establish buy-in and identify champions at the local level.
Recommended Next Steps

Work with OACCAC and Health Quality Ontario (HQO) to align these best practices and strategies and to support the standardization of care delivery within the palliative care Integrated Client Care Project (ICCP) early implementation sites and incorporate learning in terms of continuing quality improvement.
Summary

• The implementation of a consistent system wide approach to HPC care paths and tools appears to be of great interest across the system.

• This consistent approach could produce many tangible and valuable benefits across the chronic care continuum, including enhanced:
  – **Communication** - Fewer misunderstandings; easier communication; people using the same language and terminology.
  – **Use of Resources** – Better Interdisciplinary team collaboration and alignment; Smoother cross care setting transitions;
  – **Time Management** – Earlier identification and response to patients needs;
  – **Financial Management** - Efficient and effective use of health care resources.
  – **Satisfaction** - Enhanced patient, family and service provider satisfaction and higher quality of EOL across chronic diseases
  – **Knowledge Sharing** - Easier knowledge transfer due to common understanding and integration efforts.
Concluding Remarks

• Instead of using multiple tools inconsistently or trying to find the “perfect tools”, we could begin this pivotal process by consistently using throughout the system of care the “best available tools and approaches” and monitor quality improvement.

• Therefore, it is hoped that strong collaboration and continued consultation with other chronic disease professionals, and utilizing this existing body of work as the foundation will help to propel the selection and adoption of appropriate and consistent HPC – CDM best practice standards in Ontario.
Section Two: Beth Lambie

To gather and consolidate existing information and knowledge about current palliative hospice care model(s) in all care settings
Presentation Overview

1. Why do this review?
   – Objectives
   – Purpose and focus
2. Review Process & Limitations
3. Findings
   – Part one
   – Part two
   – Part three – refer to discussion paper
4. Summary Reflections

Timeframe – 20 minutes.
Objectives

• To gather and consolidate existing information and knowledge about current palliative hospice care model(s) in all care settings

• Using this information, assess readiness for the “new model” at the regional level and at the sector specific level
Purpose & Focus

1. **Context and common understanding**

2. **Assessing readiness for change**
   - Emphasis on progress and what is already done.

3. **Practical Focus**
   - check listing of core elements
   - provide practical specificity in terms of where we are between our “current model” and our “new model”.
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.

From - Advancing High Quality, High Value Hospice Palliative Care in Ontario (2011)
Proposed New Model:

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.

From - Advancing High Quality, High Value Hospice Palliative Care in Ontario (2011)
Purpose and Focus

Current model

Practical specificity re. readiness

New model

Gaps/Issues/Negative

√

positives
Purpose and Focus

“We are being asked to adopt a ‘new’ model of Hospice Palliative Care delivery. We all know that our current system needs improvement and we all agree, at a conceptual level, with the ‘new model’. However, beyond the conceptual and philosophical what is the ‘it’ that we are promoting?

We need practical tools to understand the specifics of what the new model would look like in our own region and in the places where we work. We need to understand in specific terms where we are and how, in practical terms we can move this model forward into every care setting where patients live and die”

- Excerpt from HPC Provider letter to EOLCN Director
Review Process

**Primary Information sources** (Each source was reviewed for reference to models of HPC):

- LHIN specific HPC reports, documents, presentations, websites from across Ontario.
- LHIN specific survey responses:
  - in May 2009 for inclusion in Provincial Inventory (24).
  - February 2010 to participants of the June 23\textsuperscript{rd} 2009 *Strategy Development Workshop Improving the Quality of Hospice Palliative Care across Ontario*.
  - LHIN specific survey responses submitted by each LHIN office in the fall of 2011 as foundational information for the Ontario Palliative Care Engagement Strategy.
- Minutes and discussion notes from PEOLCN and QHPCCO meetings,
- Sector specific / organization specific websites and HPC program descriptions,
- Outcomes from discussions with key informants,
- Outcomes from PEOLCN member feedback.
Review Process

The outcomes from the above review are referenced against descriptions of models of care as articulated in a **broader body of information** including:

- Recent report released by the World Health Organization,
- Report from CCO which makes specific recommendations regarding regional models of care and the organization and delivery of Palliative Cancer Care in Ontario,
- Selected articles, summary reviews and reports,
- The report from Ontario’s recent engagement process *Advancing High Quality, High Value Hospice Palliative Care in Ontario*,
- The System Design Framework for HPC in Ontario,
- Key common elements/components which have been identified as being the most important to enhance HPC service delivery,
- The Canadian Hospice Palliative Care Model to Guide HPC.
Review Process

Deconstruct/ ‘unpack’ & then reconstruct

• *Part One*
  – practical check list / template, with core elements to use in describing and creating HPC models of care at a regional level and a sector specific level
  – composite of many descriptions.

• *Part Two and Part Three*
  – Expand upon each of these core elements
  – Apply these checklists / templates to review current status of HPC models of care at a
    • regional level and
    • sector specific level (not addressed in this presentation).

Discussion paper in 3 parts – available after today’s meeting
Review Process

Part 1: Multidimensional Model of Care Checklist Built from Information Sources

Part 2 & 3: Compare & Contrast

Information Sources: Descriptions of Models by Region and Sector

Insight into State of Readiness for New Model
Limitations

Limitations

• No specific regions or specific programs are named in this review.

• This review is primarily limited to “what is written” (Some validation was done with key informants).

• No simple schematic - It will still be necessary to depict various aspects of this model with category-specific schematics.
Part one – Describing HPC models: Findings

Q - What is meant by the term “model of care” in HPC?
A - Same term – different ideas
The term “model of care” means different things to different people and means different things in different contexts. This term is used as a descriptor at a micro level (e.g. one specific ward/unit), at a macro level (e.g. national policy) and everywhere in between.

Q - How do we currently describe models of hospice palliative care in Ontario?
A – Hundreds of descriptors
Models of HPC - Multidimensional

For the purpose of this discussion paper we considered that a model of care:

• Is a multidimensional concept that defines the way in which health care services are delivered,
• Consists of defined core elements and principles
• Has a framework that provides the structure for the implementation and subsequent evaluation of care.

Part One - Findings

**Q** - What key components of a comprehensive model of care are currently described in Ontario by:

- LHIN region
- HPC setting (24/7 setting)?

**A** – Composite, inclusive, multidimensional listing of elements (refer to discussion paper part one)
Part One - Takeaways

Several key takeaway messages emerge from *Part One*:

- Models with a multidimensional focus
- High level of agreement on core elements – flexibility on application
- Philosophical and practical
- Alignment with previous work
- Alignment with Ontario’s new model (when viewed as a composite) – therefore checklist serves as a practical proxy for the “new model”
- General, high level enough, to allow a mix of services that are patient focused, based on the patient’s needs
Cannot capture all the dimensions in one schematic - (it would look something like this!!)
Schematic - capturing essence of philosophical/conceptual aspects “new model”
“Palliative Care is often described as a ‘philosophy of care’. It is a philosophy that has practical, tangible ways in which it can be applied. Our descriptions of models of care need to go beyond descriptions of the philosophy to include descriptions and evidence of how we apply this philosophy/approach in our regions and care settings.”

-Excerpt from HPC Provider letter to EOLCN Director
Part Two- Regional models of HPC: Findings

Q - To what degree is there evidence that these core elements are embraced and implemented at the regional level in Ontario?
A – High degree of evidence. (See summary tables)

Q - Given the answers to the above question, what is the state of readiness for a new model of HPC service delivery at the regional level in Ontario?
A – High state of readiness
Part Two – Findings

Evidence of core elements

Systematic review

Table 1b Regional Model of Care – HPC in Ontario – State of readiness for Next Steps

<table>
<thead>
<tr>
<th>Core components of a Regional HPC model / system</th>
<th># of LHINs showing evidence of specifics of the “new model” of HPC</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
</tr>
<tr>
<td>1 - Vision/values/principles/philosophy</td>
<td></td>
</tr>
<tr>
<td>2 - Articulated understanding of how HPC is provided and endorsement of CHPCA model specifically:</td>
<td></td>
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<tr>
<td>• Patient/family as centre of care teams</td>
<td></td>
</tr>
<tr>
<td>• The Role of Hospice Palliative Care during illness – simultaneous care, early intervention, inclusion of bereavement in HPC role</td>
<td></td>
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<tr>
<td>• Interdisciplinary nature of HPC including volunteers</td>
<td></td>
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<tr>
<td>• All ages, ethnicities &amp; geographic regions</td>
<td></td>
</tr>
<tr>
<td>• Need for HPC in all advanced chronic diseases including but not limited to cancer</td>
<td></td>
</tr>
<tr>
<td>• Provider Roles in Hospice Palliative Care – primary, secondary, tertiary</td>
<td></td>
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<tr>
<td>*Relationship between Specialist HPC and Primary Care</td>
<td></td>
</tr>
<tr>
<td>• The foundational concepts as described by CHPCA</td>
<td></td>
</tr>
<tr>
<td>Domains of issues associated with illness and bereavement</td>
<td></td>
</tr>
<tr>
<td>Essential and basic steps during a therapeutic encounter</td>
<td></td>
</tr>
<tr>
<td>The principal activities of Hospice Palliative Care</td>
<td></td>
</tr>
<tr>
<td>3 - Evidence of systematic planning – Framework/design</td>
<td></td>
</tr>
<tr>
<td>4 – Care Settings and Services: See below for details</td>
<td></td>
</tr>
<tr>
<td>• Concept of full continuum endorsed</td>
<td></td>
</tr>
<tr>
<td>• &gt; 50% of core care settings/services are in place</td>
<td></td>
</tr>
<tr>
<td>• Full continuum or current concrete regional plans to address gaps already in place</td>
<td></td>
</tr>
<tr>
<td>5 – HPC in each relevant sector/service where patients die See below for details</td>
<td></td>
</tr>
<tr>
<td>• Concept endorsed - need for HPC in each setting where patients die</td>
<td></td>
</tr>
<tr>
<td>• Actual availability of HPC program in all care settings</td>
<td></td>
</tr>
</tbody>
</table>

Unable to assess on LHIN by LHIN basis
Part Two – Findings
Evidence of core elements

<table>
<thead>
<tr>
<th>6 – Integration/ Linkages between sectors</th>
<th>See specific integration items below</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Concept endorsed</td>
<td>√</td>
</tr>
<tr>
<td>• Common practice and processes:</td>
<td>√</td>
</tr>
<tr>
<td>Common language/tools (ESAS, PPS)</td>
<td>√</td>
</tr>
<tr>
<td>Implementation of CCO Clinical symptom management guides etc. in at least one care setting</td>
<td>√</td>
</tr>
<tr>
<td>Other clinical pathways care plans that span all sectors/services implemented in all settings</td>
<td>√</td>
</tr>
<tr>
<td>Other clinical pathways sector/disease specific with relevance to HPC implemented</td>
<td>√</td>
</tr>
<tr>
<td>Cross sector pathways for pt. flow - defined (e.g. Clear criteria differentiating roles of various sectors/services within a given area with clear transition processes (hand-offs) between sectors/services and clear access points/processes for admission and discharge to/from sectors/services)</td>
<td>√</td>
</tr>
<tr>
<td>Cross sector pathways for pt. flow - implemented fully across all sectors and all geography</td>
<td>√</td>
</tr>
<tr>
<td>• Collaborative structures/virtual clinical programs:</td>
<td>√</td>
</tr>
<tr>
<td>Venues for integrated pt. specific care planning (e.g. Cross sector patient specific rounds)</td>
<td>√</td>
</tr>
<tr>
<td>Venues for collaborative process development (e.g. EOLCN tables etc.)</td>
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<tr>
<td>Shared communication/IT with accessible patient records between most sectors/services in LHIN</td>
<td>√</td>
</tr>
<tr>
<td>Defined &amp; implemented access to specialist expertise (24/7) - all care settings and services</td>
<td>√</td>
</tr>
<tr>
<td>• Cross sector education (some mention of cross sector education)</td>
<td>√</td>
</tr>
<tr>
<td>• Cross sector communication venue, tool, strategy</td>
<td>√</td>
</tr>
<tr>
<td>• Organizational integration and/or discussion underway about organizational (or back office) integration for specific HPC services</td>
<td>√</td>
</tr>
<tr>
<td>7) Human Resources</td>
<td>See below for details</td>
</tr>
<tr>
<td>• Key leaders and Key PC clinicians identified and in place</td>
<td>√</td>
</tr>
<tr>
<td>• HR adequate &amp;/or plan in place</td>
<td>√</td>
</tr>
<tr>
<td>8) Shared Accountability</td>
<td>See specific accountability items below</td>
</tr>
<tr>
<td>• Evaluation/system level reporting</td>
<td>√</td>
</tr>
<tr>
<td>• Initial Infrastructure – LHINs &amp; EOLC/HPC Networks / Program - planning</td>
<td>√</td>
</tr>
<tr>
<td>9) Policy /Funding / Provincial &amp; LHIN level readiness etc.</td>
<td>√</td>
</tr>
</tbody>
</table>
## State of readiness

### 1. Vision/values/principles/philosophy
Each region has a critical mass of providers who understand, articulate and embrace the values, vision, and conceptual principles of the “new model”. Much education has already been done to advance an understanding of HPC in every region in Ontario.

### 2. Evidence of endorsement of CHPCA understanding of how HPC is delivered (Domains of issues, primary, secondary, tertiary level care, link with CDM etc.)

<table>
<thead>
<tr>
<th>High level of readiness to continue to advance the underlying principles of HPC as articulated in “new model’. Education needs to continue and there is an informed group to build capacity in others.</th>
</tr>
</thead>
</table>

### 3. Evidence of systematic planning – Framework/design – There is evidence of systematic planning for HPC.

<table>
<thead>
<tr>
<th>High level of readiness. The already completed regional planning will serve as an important foundation moving forward. No LHIN region will be starting from scratch.</th>
</tr>
</thead>
</table>
LHIN Survey 2011 - Does your LHIN have a specific framework for HPC delivery in the region? n=14

- Yes - Ontario's System Design Framework for HPC: 6
- Yes - A strategic plan: 2
- Yes - The End of Life Care Network accountability for our region: 1
- Yes - "LHIN Pall. Care model & enhanced HPC funded program": 1
- No - but evidence of planning: 1
- Yes - CHPCA model: 1
- No - but evidence of planning and desired outcomes articulated: 1
## Part Two – Findings

### State of Readiness

<table>
<thead>
<tr>
<th>4. Care sectors and services – A full continuum of care settings is available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Each region shows endorsement of the concept of many care settings and services being required to provide a regional system of HPC. Most regions show cross sector representation at their planning tables. No region claims to have a full continuum of care settings and services for provision of HPC however it is estimated that in most regions &gt; 50% of core care settings/services are in place. In a number of regions, feasibility studies are being undertaken regarding increasing the numbers of residential hospices.</td>
</tr>
</tbody>
</table>
## Part Two – Findings

### State of Readiness

<table>
<thead>
<tr>
<th>5. Programs within all care settings – In each care settings where patients die there is a HPC program</th>
</tr>
</thead>
<tbody>
<tr>
<td>All regions endorse the principle that HPC should be available in all care settings where patients live and die. All regions show HPC ‘programs’ in at least one care setting. Several regions have systematically examined access to HPC within each of their care settings using the practical checklist of elements from the system design framework (17) (realm 2). (Refer to part 3 of this discussion paper for details of sector specific programs)</td>
</tr>
</tbody>
</table>
## Part Two – Findings
### State of Readiness

<table>
<thead>
<tr>
<th>6. Integration / collaboration / Linkages – Services and sectors are linked by common practice, processes, structures and education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All regions endorse the principle. All regions have initiated some integrative/cross sector/collaborative work including cross sector HPC education &amp; use of common tools. All regions have some venue for cross sector planning. No regions have 24/7 access to specialist level HPC nor cross sector pathways for pt. flow implemented fully across all sectors and all geography of the region.</strong></td>
</tr>
<tr>
<td><strong>High</strong> level of readiness in terms of endorsing the principle and having the stage set for acceptance of cross sector activities. <strong>Low</strong> level of readiness in terms of having fully developed examples of fully integrated cross sector service delivery. A few local examples in a small geographic area can serve as possible pilot sites.</td>
</tr>
</tbody>
</table>
HPC program- 24/7 supports

LHIN Survey 2011 - Does your LHIN have a funded program for 24/7 HPC supports? n = 14

- No (with caveats on 2 of the "nos")
- Yes with explanation of limitations - program that helps support providers in community (1), partial in terms of care settings and geography (1), "funded APNs but could not enforce it" (1), A@H funding via a hospital (1)
- No answer
HPC cross sector program

LHIN Survey 2011 - Does your LHIN have a formal cross sector palliative care program? n=14

- No
- Yes with qualifiers - EOLC/HPC Network is the program(2), shared care model that navigates between programs (1), caveates in terms of which sectors and what geography are served(1).
LHIN Survey 2011 Do you have formally adopted palliative care pathways within your region? n=14

- Yes, (with qualifications) - Specific care paths include: CCO Symptom Management Guides and Collaborative Care plans (3), Symptom Response Kits & local pathways (1), no example given(2),
- Blank
- Underdevelopment
- Don’t know

No: 5
Yes, (with qualifications): 1
Blank: 1
Underdevelopment: 1
Don’t know: 6
## Part Two – Findings

### State of Readiness

#### 7. Human Resources

Most regions have key leaders and key HPC clinicians identified. Few regions have an HR plan or current adequate number of HPC providers. **High** level in terms of having critical mass of leaders and providers currently available to advance next steps. **Low** level of readiness in terms of HR plan in place.

#### 8. Accountability – Shared accountability across sectors

All regions have some established venue for shared planning. Several LHINs have included HPC in annual business plan. Few regions have an established system for cross sector evaluation/system level reporting. **High** level of readiness in terms of established venues and alignment between networks and LHINs. **Low** level of readiness in terms of already established frameworks for cross sector ongoing evaluation.

#### 9. Policies/ Funding / overall LHIN readiness

All of the LHIN regions can garner stakeholder involvement within 5 months or less. Most LHINs have provided some additional funding for HPC. **High** level of readiness in terms of provincial level support and readiness. High level in terms of overall LHIN readiness.
Shared Accountability Across Sectors

LHIN survey 2011 - Collaboration between LHIN and EOLC/HPC Networks n=14

- LHIN has formalized relationship with EOLCN in terms of seeking advice &/or has membership on the Network
- LHIN and EOLC/HPC Network function independently with no formalized system for information sharing &/or membership
Part Two- Regional models of HPC: Review of Findings

Q - To what degree is there evidence that these core elements are embraced and implemented at the regional level in Ontario?

A – High degree of evidence.

Q - Given the answers to the above question, what is the state of readiness for a new model of HPC service delivery at the regional level in Ontario?

A – High state of readiness
Part Three- Sector Specific Models
refer to discussion paper for outcomes

SECTOR-SPECIFIC LEVEL in Ontario

1. Vision/values/principles/philosophy & evidence of strategic planning for HPC
2. How this particular sector typically describes its model of care for HPC service delivery (may include comments on configuration of beds, staffing types/levels, funding etc.)
3. Description of how specialist level expertise is accessed (including a listing of professionals involved, funding/service agreements etc.)
4. Explanation of the relationship between primary care and specialist level care (e.g. consultation only, shared care etc.)
5. Information about access to HPC in non-business hours (24/7 access)
6. Admission criteria/referral processes (including description of population served and population not served)
7. How / what education about HPC is delivered
8. Key Organizational contact
9. Interdisciplinary expertise
10. Linkages with partners
11. Reporting, evaluation, CQI and data accountability
12. Relevant accreditation standards/ best practice guideline and awareness of the CHPCA Model to Guide Hospice Palliative Care
Summary Reflections: Is the System Ready?

The “Regional System” of Hospice Palliative Care in Ontario is really a “system of systems”.

(S. Allan -2008)
Summary Reflections: Is the System Ready? - Yes

• Foundation is already in place – in all regions
• Building is happening in all regions
• Some areas have well developed programs that are being renovated or expanded to accommodate CDM etc.

(Analogy – S. Allen)
Proposed New Model:

- 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.

- **Uniquely Palliative**
- Good care
- New service delivery elements

(practical implications/elements for each part of this model)

*From - Advancing High Quality, High Value Hospice Palliative Care in Ontario (2011)*
“Getting it right” for Palliative Care helps us to “get it right” for the system

“In the end, our society’s ability to realize its potential will be related to its success at relieving suffering. The health and compassion of our communities will be related to the degree of integration of hospice palliative care into all aspects of our healthcare system.”

The CHPCA Model to Guide Hospice Palliative Care
Validation

• New model is the right model and it is described over and over again in various aspiration models of care.

• Next steps, as articulated in the report *Advancing High Quality, High Value Hospice Palliative Care in Ontario (2011)*, are the right steps
We are ready!

“We know enough,
We agree enough,
We have talked enough,
We have planned enough,
We are ready to implement.”

- Excerpt from HPC Provider letter to EOLCN Director
The system is important for the patients

Excerpt from email for patient 2006 “the before”:

“It has been a struggle. The physical struggle is one thing, but worse still is the sense that I am a burden to everyone. Let me be clear – the people are wonderful but it is as if all the workers have to go out of their way to actually provide the care and connections that are needed. **There just doesn’t seem to be a system.** It is as if my situation is a ‘one-off’ and everyone is piecing it together as we go. Have people not died before me???”

(Excerpt used with permission.)
The system is important for the patients

Excerpt from email for patient 2011 “the improved”:

“All the way along, I felt as if together they formed a strong set of arms guiding me through. People from the hospital, the Access Centre, the [service provider agency] and the Hospice all worked together and worked with me...... I hear all of you talking about a ‘good death’ – sounds like an oxymoron until you are near it. I think I will have a good death and I am not afraid”

(Excerpt used with permission.)
Thank You

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