



# Advancing High Quality, High Value Palliative Care in Ontario

**A Progress Report on the 10th Anniversary of  
*A Declaration of Partnership and Commitment to Action***

**Quality Hospice Palliative Care  
Coalition of Ontario**

December 2021



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# Introduction to the Quality Hospice Care Coalition of Ontario

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The Quality Hospice Palliative Care Coalition of Ontario's (QHPCCO or just "Coalition") was formed in 2010 to focus attention on the need for high quality palliative care in Ontario. The Coalition is comprised of provincial associations representing over 1,500 health service and community support organizations that provide or have a role in the provision of hospice palliative care to the people of Ontario. These associations represent over 275,000 health care professionals, health care workers, and volunteers.

- ▶ [AdvantAge Ontario](#)
- ▶ [Association of Family Health Teams of Ontario](#)
- ▶ [ALS Canada, Ontario Division](#)
- ▶ [Alzheimer's Society Ontario](#)
- ▶ [Bereavement Ontario Network](#)
- ▶ [Canadian Cancer Society, Ontario Division](#)
- ▶ [Catholic Health Association of Ontario](#)
- ▶ [Heart & Stroke Foundation of Ontario](#)
- ▶ [Hospice Palliative Care Ontario](#)
- ▶ [Home Care Ontario](#)
- ▶ [Lakehead University](#)
- ▶ [McMaster University](#)
- ▶ [Nurse Practitioner Association of Ontario](#)
- ▶ [Ontario Association of Paramedic Chiefs](#)
- ▶ [Ontario Association of Social Workers](#)
- ▶ [Ontario Caregiver Coalition](#)
- ▶ [Ontario College of Family Physicians](#)
- ▶ [Ontario Community Support Association](#)
- ▶ [Ontario Long Term Care Association](#)
- ▶ [Ontario Medical Association](#)
- ▶ [Palliative Care Consultants Network](#)
- ▶ [Pregnancy and Infant Loss Network](#)
- ▶ [Registered Practical Nurses Association of Ontario](#)
- ▶ [Registered Nursing Association of Ontario](#)
- ▶ [University of Toronto](#)

## What is the Declaration of Partnership and Commitment to Action?

In 2011, the Coalition, in partnership with the Ministry of Health and Long-Term Care and the Local Health Integration Networks brought health service providers together to set forth a new vision and a new plan for palliative care in Ontario. The result was the publication of **Advancing High Quality, High Value Palliative Care: A Declaration of Partnership and Commitment to Action**, in December 2021.

Through the action commitments in the Declaration, the partners committed to providing better care for Ontarians at end of life while better managing health care resources over time. The Declaration sets out individual and collective commitments, common priorities, and actions to improve and optimize palliative care in Ontario. The goal is to improve the experience of the individuals and caregiver, the quality of care, and value the system delivers. The Declaration identifies the steps to provide equitable access to safe, comprehensive and high-quality palliative care and support for individuals and their families.

On this 10<sup>th</sup> anniversary of the publication of the Declaration of Partners, the Coalition has reviewed the progress of the action commitments and identified gaps that remain to be closed. This report details progress, gaps, and recommendations for future action to further improve access to high quality hospice palliative care.

# Executive Summary of Report

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**Recommendations for future action fall into six Key Themes of work to address the gap between the current state and the new model of care.** This executive summary highlights the significant progress made in the last 10 years and recommendations on how to address current gaps moving forward.

## Advancements in the Past 10 Years

### Key Theme 1: Broaden access and increase timeliness of access

- ▶ Increased use of standardized tools to identify patients who would benefit from palliative care
- ▶ Successful initiative to improve accessibility to palliative care includes:
  - ⇒ Health Services Delivery Framework by the Ontario Palliative Care Network including care for marginalized and vulnerable populations
  - ⇒ Ontario Renal Network palliative care strategies for patients with chronic kidney disease
  - ⇒ Strategic investments by government to increase the number of hospice beds and long-term care beds
  - ⇒ Hospice Palliative Care Ontario initiated a Rural Palliative Care Community of Practice and a Virtual Compassionate Care Community Centre

### Key Theme 2: Strengthen caregiver supports

- ▶ Creation of a Caregiver and Client Bill of Rights and Bill C-220 for extended bereavement leave
- ▶ Establishment of various caregiver educational and outreach support programs across Ontario

### Key Theme 3: Strengthen service capacity and human capital in all care settings

- ▶ Development of the Ontario Palliative Care Competency Framework
- ▶ Resources available at primary, secondary, and tertiary levels for training and palliative care expertise through several organizations (e.g. Ontario Palliative Care Consultants Network, Canadian Association of Schools of Nursing, Pallium Canada, and Hospice Palliative Care Ontario)

### Key Theme 4: Improve integration and continuity across care settings

- ▶ Integration of navigator role into palliative models of care
- ▶ Utilization of Client Health and Related Information System (e-Health platform) by Health Shared Services Ontario
- ▶ Standardization of assessment and competency via:
  - ⇒ Earlier Identification Expert Panel
  - ⇒ Advanced Care Planning

## **Key Theme 5: Strengthen accountability and introduce mechanisms for shared accountability**

- ▶ Creation of a Palliative Care Quality Standard
- ▶ Ongoing research and reporting on provincial and regional indicators of system performance
- ▶ Development of Quality Improvement Plans for standardized hospice palliative care indicators and evaluations
- ▶ Hospice Performance and Outcome Measurement Platform offers tools on data collection and analysis for the hospice sector on care quality and impact.

## **Key Theme 6: Build public awareness**

- ▶ Targeted public awareness campaigns in print and social media promoting Advance Care Planning and general public awareness of hospice palliative care
- ▶ Educational events and webinars for caregivers and the general public on Advance Care Planning, Health Care Consent, caregiving, and support for the caregiver

## **Recommendations to address existing gaps**

### **Key Theme 1: Broaden access and increase timeliness of access**

- ▶ Strengthening partnerships with groups that work with underserved populations for integration of equitable access and inclusion
- ▶ Advocating for removal of funding and coding barriers to enable comprehensive access to palliative care across all sectors
  - ⇒ Development of disease-specific models of palliative care i.e. chronic heart failure, progressive neurological disease, progressive respiratory disease, frail seniors, those with dementia

### **Key Theme 2: Strengthen caregiver supports**

- ▶ Continue to involve caregivers in decision making, system planning, and evaluation
- ▶ Implement the Caregiver and Client Bill of Rights and promote caregiver leaves
- ▶ Improve caregiver benefits and investments for benefit and support programs
- ▶ Improve and increase access to home, respite, and psychosocial care

### **Key Theme 3: Strengthen service capacity and human capital in all care settings**

- ▶ Integration of standardized palliative care training into academic curriculums and mid-career specialist programs
- ▶ Reframe hospice palliative care as a holistic approach to care instead of separate discipline
- ▶ Strategic investments for increased funding for home and community-based care services that keep people out of hospital

#### Key Theme 4: Improve integration and continuity across care settings

- ▶ Establish universal, evidence-based, person-directed care standards. i.e. common set of clinical best practices
- ▶ Create strategies to effectively implement the Delivery Framework in all regions

#### Key Theme 5: Strengthen accountability and introduce mechanisms for shared accountability

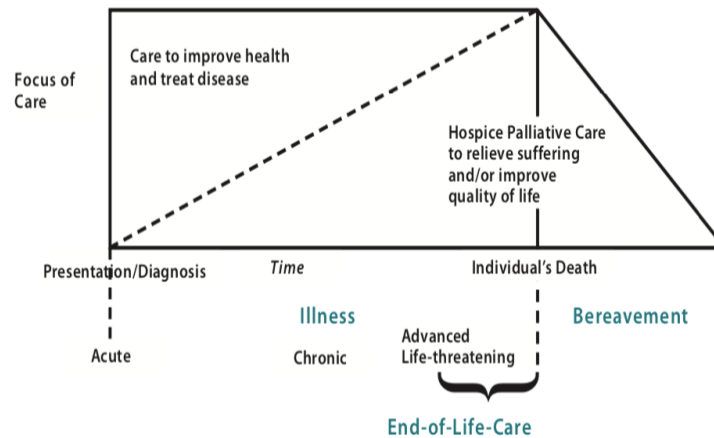
- ▶ Establish accountability mechanisms within Ontario Health and its regions that support shared accountability
- ▶ Consult with and include Coalition members and palliative care experts in decision-making
- ▶ Fund and support research on shared accountability and performance
- ▶ Continue to support improvements in needs assessments, evaluations, system-wide data collection, and quality improvement responses

#### Key Theme 6: Build public awareness

- ▶ Develop programs, awareness campaigns and strategies to improve understanding of palliative care
- ▶ Development, testing, and formalization of educational training programs
- ▶ Planning and development of accessible virtual support and resource hubs

# What is hospice palliative care?

Hospice palliative care – also simply called “palliative care” – is a philosophy of care. Our definition and understanding of hospice palliative care is adapted from the Canadian Hospice Palliative Care Association Model to Guide Hospice Palliative Care (2002), as seen in the diagram below:



## New model for palliative care:

The evidence is overwhelming: excellent palliative care has the same elements as excellent management of chronic disease. Ontario's health care system needs to shift to a single, cohesive delivery model that integrates care and support for adults and children with chronic disease at every stage – from diagnosis until death and through bereavement.

## Expected implications + outcomes of new model:

1. A health care system that:
  - ▶ is patient-centered
  - ▶ achieves better outcomes
  - ▶ is more cost effective
2. Adults and children with chronic disease and their informal caregivers will have access to:
  - ▶ comprehensive, integrated, personalized health care
  - ▶ community and social services that respond to their needs, goals, and personal circumstances
3. The right supports to:
  - ▶ remain in their communities
  - ▶ have their chronic disease managed optimally, and
  - ▶ relieve the burden on informal caregivers

# Introduction

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## Our 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.

## Top 4 Goals:

- I. **Quality:** To improve client/family, caregiver, and provider experience by delivering high quality, seamless care and support.
- II. **Population Health:** To improve, maintain and support the quality of life and health of people with progressive life-limiting illnesses.
- III. **Sustainability:** To improve system performance by delivering better care more cost-effectively and creating a continuously self-improving system.
- IV. **Provider Well-being:** To improve the work-life of providers.

**This 10-Year Review of the Declaration of Partnership** provides an update on each of the six key themes identified in the original document. The review summarizes activities and advancements over the past 10 years, ongoing gaps, and recommendations for the next 10 years. It will support development of a provincial palliative care framework, which was commissioned in the Compassionate Care Act (2020).

## Key Theme 1: Broaden access and increase timeliness of access

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### Summary: Past 10 Years

- ▶ Increased support for people to access and navigate services, including tools to help patients identify symptoms that could be eased through palliative care.
- ▶ Early identification earmarked as a key quality improvement goal by Health Quality Ontario (now within Ontario Health).
  - Increased use of standardized tools for early identification of people who would benefit from palliative care, and early identification increasingly incorporated into primary care practice, including within electronic medical records.
- ▶ The Ontario Palliative Care Network's Delivery Framework describes a pathway to guide care delivery following identification of the potential for palliative care needs. This framework is being used across the province to guide planning.
- ▶ Increased use of standardized approaches and tools for assessment of palliative care needs in multiple settings.
- ▶ The Delivery Framework details key elements of palliative care delivery for First Nations, Inuit, Metis, and Urban Indigenous Populations, and for the homeless and structurally vulnerable populations. The Framework was developed in consultation with these communities and is being used in some areas of the province.
- ▶ The Ontario Renal Network established palliative care priorities and strategies for individuals with chronic kidney disease.
- ▶ Virtual care has expanded rapidly during the COVID-19 pandemic and allowed easier access for multiple populations.

### ***According to the Canadian Hospice Palliative Care Association:***

*Almost half of Canadians (47%) say hospice palliative care is available to all those at the end of their life regardless of their illness.*

*Only 19% say it is available to those dying of life-threatening illnesses. However, one-third of Canadians*

*(34%) are not sure to whom hospice palliative care services are available*

- ▶ Hospice Palliative Care Ontario's (HPCO) Compassionate Communities initiative uses quality of life and outcome measurement tools to track population wellness. A Virtual Compassionate Care Community Centre was developed during the COVID-19 pandemic, and provides virtual support for isolated seniors, caregivers, and people with serious illness.
- ▶ HPCO's Rural Hospice Palliative Care Community of Practice facilitates dialogue and reinforces best practice for rural hospice palliative care.
- ▶ Strategic investment to expand the number of hospice residences has kept thousands of end-of-life patients out of hospitals.

## Ongoing Gaps

- ▶ Limited implementation of the Delivery Framework recommendations for First Nations, Inuit, Metis, Urban Indigenous Populations, the homeless, and vulnerably housed.
- ▶ Lack of key elements of the Delivery Framework for other populations, including people living with disabilities, substance use disorders, and mental illnesses; incarcerated individuals, low-income individuals, the 2SLGBTQ+ community, different language and cultural communities, and other underserved groups.
- ▶ Lack of palliative care models in disease-specific programs including chronic heart failure, progressive neurological disease, progressive respiratory disease, frail seniors, and those with dementia.
- ▶ The focus of palliative care remains primarily on supporting people in their last months of life (end-of-life care) rather than access to palliative care from the time of diagnosis.
- ▶ Lack of research and action on equitable access to comprehensive palliative care for diverse and underserved populations.

*Some groups lack comprehensive access to appropriate support and resources - this is especially true for rural, remote, diverse, and/or underserved communities. Additionally, caregivers are often not prepared to respond adequately to these communities. Both individuals and caregivers in key care settings should benefit from improved navigation and access to supports.*

## Recommendations: Next 10 Years

### Quick Wins:

- ▶ Engage with leaders and community members to identify how to increase support for BIPOC, 2SLGBTQ+ individuals, as well as persons living with disabilities, and those experiencing homelessness.
- ▶ Health equity should be a priority: strengthen partnerships with Indigenous groups and interest groups that work with diverse and underserved populations in order to create culturally sensitive programs and improve access to care.
- ▶ A focus on equitable access. Diversity and inclusion should be integrated into every aspect of palliative care.
- ▶ Remove funding and coding barriers to enable comprehensive access to palliative care across all sectors, settings, and professions.
- ▶ Develop strategies and supports that promote access to palliative care from the time of diagnosis and throughout a person's health and aging journey.

### Long-term Solutions:

- ▶ Develop strategies in collaboration with diverse and underserved populations and those who provide care for them to adapt and implement the Delivery Framework for those individuals.
- ▶ Develop strategies to ensure effective identification and assessment of individuals who would benefit from palliative care in all disease-specific sectors caring for individuals with life-limiting conditions.
- ▶ Establish best practices for virtual care that supports team-based care.

## Key Theme 2: Strengthen caregiver supports

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### Summary: Past 10 Years

- ▶ Caregiver and Client Bills of Rights have been developed.
- ▶ Hospice Palliative Care Ontario offers free online Caregiver learning and resources to support new and experienced family caregivers. <https://www.caregiversupport.hpco.ca/>
- ▶ Many organizations have caregiver peer support programs and actively involve caregivers in their work.
- ▶ Creation of the Ontario Caregiver Organization, which provides support and education to improve the caregiving experience.
- ▶ McMaster University offers free virtual support and courses for caregivers such as “Caregiving Essentials” and “Infection Prevention and Control” for caregivers and families.
- ▶ Wellspring offers programming and services that help people learn to overcome the challenges of caring for a loved one with cancer.
- ▶ Baycrest and the Ontario Telemedicine Network have created a web-based caregiver support group, facilitated by a social worker, for family members caring for a person with dementia.
- ▶ During the COVID-19 pandemic, Bill C-220 was introduced to extend the period of bereavement leave by five unpaid days.
- ▶ Virtual and in-person services, including grief and bereavement support, have been offered to caregivers by many organizations across the province.

*Key supports for families and caregivers are lacking or inconsistently available. This includes bereavement programs and related support. By improving caregiver support, other palliative care system outcomes should also improve.*

## Ongoing Gaps

- ▶ The Caregiver Bill of Rights and Client Bill of Rights need practical implementation strategies.
- ▶ Caregivers need more flexible benefits from both government and workplaces.
- ▶ Greif and Bereavement support is not consistently available to all.
- ▶ Use of VOICES survey has been limited primarily to the Home Care Sector.

## Recommendations: Next 10 Years

### Quick Wins:

- ▶ Develop implementation strategies for the Caregiver Bill of Rights and Client Bill of Rights.
- ▶ Continue to improve involvement of caregivers in developing goals of care and decision making.
- ▶ Improve caregivers' access to benefits and promote compassionate care leave as a workplace benefit
- ▶ Involve caregivers in system planning and evaluation of resources available to them.
- ▶ Develop resources and supports focused on improving caregiver quality of life (i.e. improve access to home care, respite, and psychosocial care).

### Long-term Solutions:

- ▶ Implement and improve financial support in the form of caregiver benefit programs.
  - ▶ Fund and expand initiatives for support (i.e. make investments to improve access to respite & caregiver support programs).
  - ▶ Improve community navigation and access to practical support and assistance for caregivers throughout the palliative care journey.
  - ▶ Expand caregiver VOICES survey to all care settings.
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## Key Theme 3: Strengthen service capacity and human capital in all care settings

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### Summary: Past 10 Years

- ▶ Improved access to palliative care expertise at the primary, secondary, and tertiary levels.
- ▶ The Ontario Palliative Care Network has published the Ontario Palliative Care Competency Framework describing the competencies for 16 different disciplines, including volunteers. For the relevant disciplines, this includes the competencies for both practice at a primary or generalist level and at a specialist level.
- ▶ Hospice Palliative Care Ontario (HPCO) provides standardized training for hospice volunteers, and standardized training for health care professionals on Person-Centred Decision Making (Health Care Consent, Advance Care Planning, and Goals of Care, congruent with Ontario law).
- ▶ Sharing of expert knowledge through communities of practice and other capacity-building activities.
- ▶ HPCO provides comprehensive standards and accreditation for hospice governance and service delivery.
- ▶ Increase in training and resources available online, especially in the COVID-19 context.
- ▶ Engagement with Ontario Base Hospital programs to promote and endorse Palliative Programs with Paramedic Services.
- ▶ Introduction of regional palliative care training for community paramedics, including screening tools and symptom management practices.

*Significant disparity exists in the province amongst care settings regarding the delivery of comprehensive palliative and end-of-life care. There is a shortage of health care professionals and volunteers with training in palliative care, grief and bereavement support, as well as a lack of standardized education. There is a need to fully engage long-term care homes, home care services, hospice residences, and primary care settings as partners to work to better understand the role each plays in delivering palliative care.*

- ▶ The Ontario Palliative Care Consultants Network offers an Advanced Palliative Practice Skills (APPS) program for PSWs, Health Care Aides, and volunteers to enhance their palliative care knowledge and skills.
- ▶ The Canadian Association of Schools of Nursing created teaching and learning resources for nurse educators on the topic of Palliative and end-of-life care.
- ▶ Pallium Canada developed LEAP courses, clinical decision and support tools, and toolkits that provide health care professionals with the essential, basic competencies of the palliative care approach.

### Ongoing Gaps

- ▶ Limited models for achieving competency that move the learner along beyond basic education and include mentorship, experiential learning, and evaluation.
- ▶ Limited mechanisms that hold organizations accountable for the competency of their workforce or that employ shared accountability between the individual and the organization.
- ▶ Lack a broad human resource plan that projects the needs for the required workforce within key disciplines.
- ▶ Need to improve access to home care and community care.
- ▶ Gaps in specialized skills and knowledge of health care providers.
- ▶ Need to strengthen palliative care delivery and build capacity in long-term care homes, hospitals, and congregate care settings (group homes, retirement homes).
- ▶ Lack of funding for specialized palliative care trainees, to address anticipated workforce gaps.

## Recommendations: Next 10 Years

### Quick Wins:

- ▶ Develop a human resource plan that projects the need for providers in key disciplines – i.e. personal support workers, palliative care physicians, nurses, and social workers.
- ▶ Improve funding to increase access to home care and community care (including adoption of ECCO model).
- ▶ Improve funding and capacity for physician training in palliative care, within medical schools and post graduate training programs.
- ▶ Support universities to build a curriculum that integrates the fundamental principles of palliative care in all areas of undergraduate and graduate training so that it is not seen as separate curricular entity and rather an approach to care.
- ▶ Provide palliative care training for long-term care homes, hospitals, and congregate care settings. Ensure that long-term care homes and other congregate care settings have established links to palliative care programs for access to specialist consultation and mentorship.
- ▶ Ensure that health care providers are offered psycho-social supports to benefit their mental health and well-being.
- ▶ Leverage non-professional community resources to optimize capacity and use of health care resources while supporting all health care providers
- ▶ Increase capacity to provide undergraduate clinical placements and other experiential learning opportunities.

### Long-term Solutions:

- ▶ Endorse a systems-thinking approach: all healthcare professionals should have basic training in palliative care and should know when to refer a patient to a palliative care specialist.

- ▶ Develop an evidence-informed human resource plan that will increase the number of palliative care specialists and providers.
- ▶ Develop accountability mechanisms for organizations that manage/employ palliative care providers to ensure that the competencies are achieved.
- ▶ Scale up existing curriculum to provide more specialized palliative care training to more health care providers.
- ▶ Expand palliative care training to all frontline paramedics.
- ▶ Create a mid-career specialist training program for palliative care to increase the number of accredited, trained physicians that develop an interest in the field mid-career.
- ▶ Increase capacity and funding for palliative residency positions (including Certificate of Added Competence and Royal College of Physicians and Surgeons of Canada programs).
- ▶ Provide enhanced education across a variety of career pathways on health promoting and palliative approaches to care, personalized care, holistic health, and community-based approaches to address population vulnerabilities and social determinants of health for health professionals and volunteers.

## Key Theme 4: Improve integration and continuity across care settings

### Summary: Past 10 Years

*Patients' healthcare needs are complex and multidimensional and therefore cannot be tended to by one single health care professional alone. Healthcare delivery requires a multidimensional approach with the integrated expertise of multiple healthcare providers. However, programs and services are often based on stand-alone models and lack the proper integration necessary to provide complete care from diagnosis to end-of-life to bereavement. Integration ensures that quality of care is maintained while the patient receives the treatment from multiple providers the delivery of services is seamless/continuous. This requires coordination, and the sharing of information between different providers.*

- ▶ Ontario Palliative Care Network's (OPCN) Delivery Framework has described an integrated model of care that is based on interdisciplinary team-based care.
- ▶ A number of the initial OHT's have identified individuals with palliative care needs as a priority population.
- ▶ Integrated hospice palliative care teams share patient caseloads - Health Shared Services Ontario (HSSO) / Ontario Association of Community Care Access Centres (OACCAC).
- ▶ HSSO/OACCAC has a province-wide e-health platform called Client Health and Related Information System (CHRIS).
- ▶ Hospice Palliative Care Ontario's is advancing materials for Advanced Care Planning (ACP).
- ▶ HSSO/OACCAC have established competencies and measures to standardize care across the province.
- ▶ The OPCN created an Earlier Identification Expert Panel. Its mandate included developing recommendations on assessment tools that would enable the earlier identification of patients who could benefit from palliative care.
- ▶ Provinces around Canada have introduced models of care that include a navigator, which serves as a single point of contact for individuals, their families, and caregivers when accessing the health care system.

### Ongoing Gaps

- ▶ Inconsistent implementation of the Delivery Framework across regions.
- ▶ Need to identify scope of best practice for palliative care.

- ▶ OHTs are at different stages of development, so palliative care integration varies across the province.

## **Recommendations: Next 10 Years**

### **Quick Wins:**

- ▶ Endorse a set of tangible universal, evidence-based, integrated care standards and guidelines to ensure delivery of quality care
- ▶ Establish effective strategies to ensure implementation of models such as the Ontario Palliative Care Network Delivery Framework
- ▶ There should be a common set of clinical best practices that are followed across all care settings to ensure that a standard of quality is maintained
- ▶ Identify those areas of clinical practice that would benefit from establishing provincial guides to best practice and develop those guides with broad clinical input.
- ▶ Continue to support integration of palliative care in OHTs across the province.
- ▶ Continue to partner with new hospices and organizations across the province to create stronger alignment, scale, and spread of compassionate communities programs.

### **Long-term Solutions:**

- ▶ Integrate palliative care into existing specialized care services for diverse and underserved populations (i.e. those accessing mental health, addiction, HIV, and housing services).
- ▶ Consider person-directed models that promote informal care integration across settings

## Key Theme 5: Strengthen accountability and introduce mechanisms for shared accountability

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### Summary: Past 10 Years

- ▶ Ontario Health – Quality (formerly Health Quality Ontario) and the Ontario Palliative Care Network (OPCN) published the Palliative Care Quality Standard which describes 13 standards from the perspective of what an individual and their family should expect.
- ▶ Caregiver VOICES survey has provided valuable feedback from caregivers on their caregiving experience.
- ▶ The OPCN is currently reporting on multiple system performance indicators at provincial and regional levels.
- ▶ The OPCN and its 14 Regional Networks provide an important mechanism for planning, providing advice, and supporting implementation and evaluation at provincial and regional levels.
- ▶ Significant uptake on developing Quality Improvement Plans (QIPs) to coordinate standardized hospice palliative care indicators and evaluation across long-term care, primary care, acute care, and community care.
- ▶ Involvement of clients and caregivers in evaluation of system performance and impact.
- ▶ Hospice Palliative Care Ontario's Hospice Performance and Outcome Measurement Platform offers tools for data collection and analysis to measure the quality and impact of hospice services.
- ▶ The Canadian Frailty Network is supporting a program of research on end-of-life and advance care planning.

*Health and social care in Ontario is delivered by independent sectors and by independent service providers. Each has its own Board of Directors, mandate, operational imperatives, and strategic direction. Within this complex context, overall shared accountability is unclear. We need to develop and strengthen shared accountability mechanisms for the care of the client and family, and to achieve the health system's goals.*

## Ongoing Gaps

- ▶ Accountability for action on reported indicators remains unclear.
- ▶ The ability to report on patient and caregiver experience using the Caregiver VOICES survey across sectors particularly in the community sector has been hampered by the costs of administering the survey.
- ▶ Accountability mechanisms for the planning and implementation of palliative care services 1) remain unclear, 2) lack sufficient strength to ensure effective implementation of recommendations.
- ▶ Inconsistent inclusion of Coalition members at the regional planning level.
- ▶ Lack of action to strengthen accreditation and academic research.
- ▶ Lack of clear accountability mechanisms for palliative care competency for organizations that employ palliative care providers.

## Recommendations: Next 10 Years

### Quick Wins:

- ▶ Establish accountability mechanisms for shared accountability between organizations and individuals.
- ▶ Continuous improvement on needs assessments and evaluations, including system-wide data collection (beyond the palliative care setting) with consistent tracking and reporting.
- ▶ Expand and ensure that the indicators being reported can be translated into quality improvement responses.

- ▶ Ensure appropriate funding for reporting on patient and caregiver experience using the Caregiver VOICES survey in all settings.
- ▶ Ensure that individuals with palliative care expertise are involved in the decision-making processes regarding palliative care services.
- ▶ Ensure that patients and caregivers are represented and participate in provincial and regional planning and implementation of palliative care services.
- ▶ Strengthen partnerships with accreditation bodies and academic institutions to improve accreditation and research
- ▶ Develop person-centered outcome measurement systems that inform quality improvement and enable shared accountability

### **Long-term Solutions:**

- ▶ Establish a clear accountability structure within Ontario Health and its regions for acting on provincial and regional strategies.
- ▶ Increase coordination between health care settings/sectors to improve accountability by ensuring that regional planning groups are strongly engaged with the broader palliative care sector
- ▶ Establish clear accountability for palliative care delivery at provincial and regional levels including accountability for indicator reporting.

## Key Theme 6: Build public awareness

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### Summary: Past 10 Years

- ▶ The Ontario Caregiver Organization created to offer programs, services, and educational resources for caregivers across Ontario.
- ▶ Hospice Palliative Care Ontario's Advance Care Planning public awareness campaign engaged thousands of people through print, social media ads, and public service announcements.

*There is a need to have clear public communication/messaging (including information on the core components of hospice palliative care) to ensure that clients, their families, health professionals and caregivers are aware of the resources and services available to them and how they can access it. This will ensure referrals are made consistently and on time. A larger awareness of all the resources will also increase community resource utilization which will lead to decreased health care costs due to prolonged, unnecessary use of hospital care.*

### Ongoing Gaps

- ▶ Limited awareness of hospice palliative care among the public and society in general. The public does not understand or relate to the definition of palliative care and the language used.

### Recommendations: Next 10 Years

#### Quick Wins:

- ▶ Continue public awareness campaigns to increase awareness and knowledge of comprehensive palliative care, and availability of patient and caregiver resources
- ▶ Develop and expand virtual platforms for palliative care and information dissemination.

#### Long-term Solutions:

- ▶ Embed hospice palliative care awareness in all levels of education, and in service clubs and social networks.
- ▶ Develop public education and awareness that demystifies death and dying and improves the public's understanding of the benefits of hospice palliative care