

# Ontario Palliative Care Network

*INAUGURAL REPORT 2016-17*



# What is the OPCN?

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The OPCN is a partnership funded by the Ministry of Health and Long-Term Care and led by CCO, the Local Health Integration Networks, Health Quality Ontario and the Quality Hospice Palliative Care Coalition of Ontario. It is putting patients and families at the centre of every decision and strengthening hospice palliative care services across Ontario. Visit the website to learn more.

[www.ontariopalliativecarenetwork.ca](http://www.ontariopalliativecarenetwork.ca)

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# Message from the Executive Co-Chairs

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When patients with life-limiting illnesses receive high-quality, well-organized hospice palliative care, they and their families benefit from reduced symptoms, increased satisfaction with overall care and greater emotional support compared with usual care. At the same time, the sustainability of the health system as a whole benefits when resources are used appropriately and efficiently.

While many healthcare providers have long offered compassionate, personalized care to patients as they near the end of life, the province requires a coordinated provincial effort to provide access to palliative care services to all Ontarians, regardless of where they live or receive their services, their age or their illness.

Working together, the Ontario Palliative Care Network (OPCN) is enabling a provincial approach to hospice palliative care improvement, using guidelines, standards, measurement, patient and provider engagement, and clear provincial and regional accountability. Collectively, the OPCN has the assets and expertise to harness the good work in hospice palliative care in the province and ensure access to high-quality, high-value hospice palliative care for all.

**MICHAEL SHERAR**  
President and CEO, CCO  
Co-Chair, OPCN  
Executive Oversight



Putting patients first could not be any more fundamental than at the end of life. As we work to identify opportunities to improve the patient experience and strengthen hospice palliative care, we have made meaningful progress. Clinical and administrative leadership has been consistently implemented across all regions in Ontario. This is a significant achievement as it results in a tremendous depth of knowledge that will benefit clinical care. Further, we have created the capacity to shape a collective understanding of high-quality hospice palliative care across all care settings where patients and their families are at the core of every decision, while remaining nimble in our approach to respond to local circumstances and implement local solutions. The work of the OPCN continues to be guided by the Declaration of Partnership and Commitment to Action as a framework for collaboration, and strong partnerships and leadership continue to drive progress toward provision of quality hospice palliative care for all Ontarians.

**BILL MACLEOD**  
CEO, Mississauga Halton LHIN  
Co-Chair, OPCN  
Executive Oversight

# Message from Key Partners

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Everyone in Ontario who needs it should be able to access high-quality hospice palliative care that reflects their values and wishes. We know from the data that all too often patients do not receive palliative care or they receive it later than they should in their illness.

The Ontario Palliative Care Network plays an important role in identifying gaps in the system when it comes to providing hospice palliative care, making more information accessible to patients, and supporting evidence-based decision-making and planning of services and resources.

Working together across the healthcare system we can make a big difference to the patients experiencing a life-limiting illness and to their loved ones, acting sooner to coordinate and offer the care, comfort and support they need much earlier in their illness. As partners, we are connected by the common goal to do better for people at the end of life and the loved ones who care for them.

A handwritten signature in black ink, appearing to read 'J. Tepper', written over a horizontal line.

**DR. JOSHUA TEPPER**  
President and CEO, Health Quality Ontario  
Member, OPCN Executive Oversight



We are all going to die — the how, when and where are the only surprises. We know that only three percent of us will die suddenly. The other 97 percent could benefit from hospice palliative care that helps manage pain and symptoms, reduce stress on the family, and support the social, practical and spiritual aspects of dying. While many Ontarians benefit from the dedication and compassion of hospice palliative care professionals and volunteers, more needs to be done to improve access and equity across the province. The partners comprising the Ontario Palliative Care Network are dedicated to improving planning, coordination, and delivery of high-quality hospice palliative care services so that all Ontarians have access to this care regardless of where they live and in any setting in which they receive care.

A handwritten signature in black ink, appearing to read 'Rick Firth', written in a cursive style.

**RICK FIRTH**  
President and CEO, Hospice Palliative Care Ontario  
Secretariat for the Quality Hospice Palliative Care  
Coalition of Ontario  
Member, OPCN Executive Oversight

# Caregiver Perspectives

Every family wants their loved ones to be well cared for, especially when they are dealing with a life-limiting illness. But – as the following two stories highlight – experiences with palliative care services in Ontario can vary widely.

## Wonderful care but frustrating gaps

In the last weeks of her life, my mother, Shirley, received excellent care from the individual nurses, doctors and personal support workers who tended to her. And yet her very difficult death highlights significant gaps in the system.

Shirley was incredibly independent. She lived on her own in a small subsidized seniors' apartment in Ottawa. She was always out and about, and took the bus to the mall every day. People often thought she was two decades younger than her 83 years because she was so active. So when she started feeling tired in the summer of 2015, she made an appointment to see her family physician, who immediately admitted her to the hospital.

Cancer. Twisted intestines. Emergency surgery. To this day, I still don't have a complete picture of my

mother's diagnosis, treatment or discharge plan. After a month of receiving round-the-clock care in the hospital, Shirley was sent home where she would receive one hour of care three times a week from a personal support worker. I kept saying that this was not enough, but I was repeatedly told that she did not meet the criteria to access a bed in a long-term care facility or hospice. I used to work in healthcare and I understand the people and processes, but trying to navigate the system and get the resources she needed was beyond frustrating even for me.

She was frail, confused by her discharge instructions, and largely alone as I live five hours away and travel frequently for work. I spent hours on the phone with a CCAC nurse practitioner who had visited my mother and concurred this was a nasty situation that was just going to get worse — quickly. The two of us tried desperately to find a bed for Shirley in a long-term care home or hospice — anywhere she could get 24-hour care.

My mother's diary entries over the following weeks are heartbreaking. She was fearful, weak and depressed. She struggled to get from her bed to the washroom or even answer the phone by her bed. Neighbours called 911 when they hadn't seen her or a care worker for two days over the Thanksgiving long weekend. She died in hospital six days later.

It is uncertain whether additional care would have extended my mother's life, but what I am certain of is that palliative care would have given her a better quality of life and death. Patients and their families need more support, with better communication and coordination among healthcare providers, and that support needs to be in place before crisis strikes. My hope is that the Ontario Palliative Care Network can work with its partners across the province to ensure that no one has to suffer the way my mother did at the end.

*Gregg's mother, Shirley, died in 2015 at the age of 83.*

**GREGG B.**

## From home to hospice, supporting a mother's wishes

My mother, Doris, was on dialysis for the last five years of her life. She was very independent and, with the help of a personal support worker who came in twice a day during the last year of her life, she was able to live on her own. She also had support from a not-for-profit seniors' organization whose mandate was to help people stay at home as long as possible through volunteers, transportation and get-togethers.

Eventually, she chose to withdraw from dialysis. I know she was tired. She lost her eyesight in her 89th year and her quality of life went down. She was able to access a spot in hospice with the help of her family doctor. He was very much involved with both my parents' care for the last 30 years.

She had a fantastic team in hospice; we couldn't have been more pleased. It was a wonderful experience in terms of people making that transition. It took all of the angst out of the whole process. We didn't do anything but get her there. They were fantastic and very supportive of her; we felt prepared. They were just great. We were able to stay with her the night she passed.

The successes were in the initiation of conversations upfront, the plans in place and the services arranged to support Mom's wishes.

*Brian T's mother, Doris, died in 2015 at the age of 90.*

**BRIAN T.**

# About the OPCN

We are a partnership of community stakeholders, health service providers and health system planners from across Ontario who are developing a coordinated and standardized approach for delivering hospice palliative care in the province.



Our work is person-centred, focusing on supporting the provision of quality hospice palliative care for all Ontarians regardless of their age or disease type.

The OPCN was launched in March 2016. Our work is guided by the report *Advancing High Quality, High Value Palliative Care in Ontario: The Declaration of Partnership and Commitment to Action* and is funded by the Ministry of Health and Long-Term Care (the Ministry). We work closely with the Ministry to ensure our work supports and aligns with *Patients First: A Roadmap to Strengthen Home and Community Care* and Parliamentary Assistant John Fraser's *Palliative and End-of-Life Care Provincial Roundtable Report* (March 2016), both of which highlight a commitment to improved access to and equity in palliative and end-of-life care at home and in the community.

## Our mandate

The OPCN will:

- **Be a principal advisor** to government for quality, coordinated hospice palliative care in Ontario
- **Be accountable** for quality improvement initiatives, data and performance measurement and system level coordination of hospice palliative care in Ontario
- **Support regional implementation** of high-quality, high-value hospice palliative care

## We will help to ensure that hospice palliative care in Ontario is:

### HIGH QUALITY

Every Ontarian receives hospice palliative care that is based on the best evidence and focused on the best outcomes.

### SUSTAINABLE

Public health care for future generations is protected through measurement and continuous improvement of outcomes and value.

### ACCESSIBLE

Every Ontarian has timely access to a healthcare provider, regardless of income level, location or health status.

### CONTINUOUS

Care received is coordinated between providers so that a consistent standard is met throughout the system.

### PERSON-CENTRED

Individuals and families are involved in developing their personal care plans and have the information they need to help them make informed decisions about care. These plans take into account their quality of life and care goals as well as personal and cultural preferences and wishes.

**The OPCN in Action:**

# Understanding the Landscape

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Some of our most important work in our inaugural year has been to describe the current state of palliative care services in Ontario and to provide advice to the Ministry about how to best meet future needs.

**“Change for the better can only come through better understanding.”**

**Jason Garay, Vice-President, Analytics & Informatics, CCO;**  
Co-Chair of the OPCN Data & Information Advisory Council

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To address an immediate need, our capacity planning strategy focused on determining where and how many residential hospice beds are needed in the province and on making recommendations to the provincial government on how best to meet those needs.

In response to a 2014 Ministry commitment to fund 200 beds in Ontario, the OPCN submitted recommendations on when and where those beds should be allocated. We are continuing to monitor residential hospice capacity on the Ministry’s behalf.

In the second phase of this work, we broadened the scope of our capacity planning to focus on the current state of palliative care services for patients with a life-limiting illness in their last year of life, receiving care in the community, home, long-term care, hospice and hospital settings. “Before you can strive to improve a system, you must first have a complete understanding of how that system works, where the opportunities to improve can be found, and how examples of excellence can be leveraged to the larger community,” says Jason Garay, CCO’s Vice-President of Analytics & Informatics.

Using the results of a Regional Capacity Planning Survey and analyses of administrative data, we developed a resource summarizing the current state, which revealed detailed variations in the utilization and administration of palliative care services at the LHIN level. This presentation was accompanied by an interactive Excel tool, which allows regional partners to explore the various metrics at the provincial and LHIN levels. This information will help each LHIN better understand and plan for services needed locally and compare themselves across other LHINs.

“This is the first time anyone has done a comprehensive, cross-sectoral assessment of palliative care services in Ontario,” says Lisa Favell, Director of System and Infrastructure Planning with CCO. “We all had a sense that there were not enough services available or they were not available in the right place. Now we have data that allows us to clearly see where palliative services are currently being delivered and who delivers those services, across the province and within the LHINs.”

To develop these new capacity planning resources, we leveraged the existing knowledge base and expertise of all our partners. We consulted extensively with Regional Palliative Care Network (RPCN) leaders, palliative care researchers and other stakeholders from across the province.

This foundational assessment of system capacity will inform our ongoing capacity planning work together and future hospice palliative care expansion in Ontario. In the next phase of our work, we will look at metrics at the sub-region level and for multiple years of data and consider how we may address key data gaps.

“From a health system transformation perspective, this data is key to driving change, as it will inform the work the OPCN will undertake in future performance indicator development. From the perspective of patients and caregivers, this work has a real impact on their lives. Data-driven, evidence-based capacity planning helps to ensure that all Ontarians have access to the palliative care services and resources they need when and where they need them.”

Lisa Favell, Director, System and Infrastructure Planning, CCO

### A Data-Driven Approach

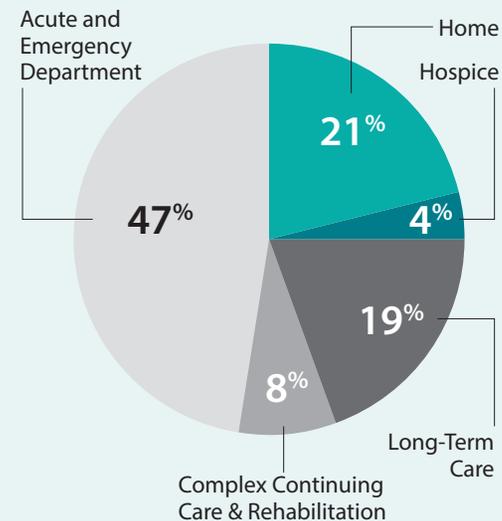
In order to understand how and where palliative services are delivered across Ontario, we are taking a data-driven and evidence-based approach. In our inaugural year, we established a Data and Information Advisory Council (DIAC), which provides ongoing strategic direction and guidance for the measurement and evaluation of provincial hospice palliative care. In addition, the DIAC works closely with the Clinical Advisory Council (CAC) to ensure that there is an exchange of knowledge between councils to support evidence-based approaches in palliative care delivery. DIAC membership includes representation from our key partner groups, system/operational leaders, other OPCN Advisory Councils and key researchers and experts in the field whose pioneering methods have advanced our understanding of palliative care across care settings.

Before the creation of the OPCN, palliative care data existed in silos. The OPCN required a new and creative data solution that could take into account the complexities of palliative care service delivery, and provide a simpler way of looking across health information systems to provide a holistic view of the patient. To do so, the OPCN took a new and innovative approach to building a data repository.

The data repository leverages CCO's rich data assets, breaking down previous data silos and enabling seamless integration across health information systems. The main benefit of the data repository is that it enables a combination of clinical concepts such as hospitalizations, unplanned emergency visits, long-term care stays, physician home services and chronic conditions, etc. By combining data with the patient cohort (i.e., patients receiving palliative services, or patients identified to be at end of life), the measurement team was able to produce a wide variety of metrics and analyses to support provincial decision-making. The most recently shared current state assessment information is an example of how the data repository can be used to support the regions with high-quality palliative care data.

### ONTARIO SNAPSHOT

## Where Ontarians are dying\*



**55%** of Ontarians currently die in hospital (includes deaths in palliative care units)

**ABOUT 10%** of all hospital deaths (or 4% of all deaths) occur in the Emergency Department

**THERE WERE 7.3** dedicated complex continuing care and acute palliative beds per 1,000 decedents, as of December 2016

\* Numbers may not add up due to rounding

“Routine public reporting of performance is a critical ingredient for a palliative care system that is responsive to the needs of patients and their families.”

**Anna Greenberg**, Vice-President, Health System Performance, Health Quality Ontario; Co-Chair of the OPCN Data & Information Advisory Council



Working in this way has many benefits, including the ability to support multiple analytic products such as surveys, scorecards and exploratory analyses. The development of a data repository allows us to introduce new concepts relatively quickly and to add in new provincial data holdings, while also ensuring consistent information across multiple projects.

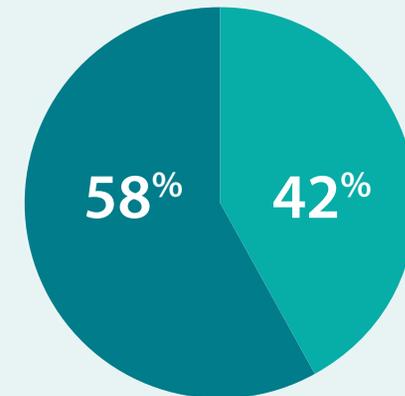
The data repository is the first step in providing high-quality palliative care data. The OPCN will undertake new work in 2017/18 to prioritize and fill in other known data gaps in palliative care. In addition, the OPCN Secretariat will produce the first provincial palliative care scorecard, supported by a performance management program to facilitate continuous quality improvement and system-level coordination.

“Building on excellent progress in recent years to link multiple administrative datasets, we can now paint a clear picture of where and when patients are receiving palliative care,” says Anna Greenberg, Vice-President of Health System Performance with Health Quality Ontario. “The data confirms that we could be doing a better job of identifying patients in need of palliative care earlier and providing more care and supports outside of the hospital.” She adds that the OPCN has begun to make this information accessible and available to enable planning and improvements for patients, and to deepen the public’s understanding of this critical part of our healthcare system.

Making sense of the delivery of palliative services across the Ontario healthcare system is complex. With the support of the DIAC and the RPCNs, the OPCN will continue to take the lead in taking a data-driven approach to understanding palliative services in our healthcare system.

#### ONTARIO SNAPSHOT

### Patients receiving palliative care



AT LEAST **58%** of decedents received palliative care services at some point in their last year of life.

OF THE REMAINING **42%** some patients may have received palliative care services but were not captured in administrative databases.

## The OPCN in Action:

# Advice on Opioid Access

In July 2016, the Ministry of Health and Long-Term Care announced its intention to delist high-strength long-acting opioids from the general formulary in order to encourage appropriate prescribing in accordance with clinical practice guidelines. However, there is recognition that these drugs play an important role in addressing palliative care needs, including necessary pain and symptom management.

“Patients requiring palliative care and experiencing complicated pain and other symptoms need access to a unique group of medications, and they would be impacted by the delisting of high-strength long-acting opioids from the Ontario Drug Benefit (ODB) formulary,” says Dr. Ahmed Jakda, the OPCN Provincial Clinical Co-Lead. “It was important that the OPCN engage with the Ministry and provide advice to ensure that patients would have access to the medications they need.”

The OPCN’s Clinical Advisory Subgroup worked closely with the Ministry’s Ontario Public Drug Programs (OPDP) division, the Ontario Medical Association (OMA) and other clinicians to develop a set of recommendations to ensure ongoing access to high-strength long-acting opioids for patients who may require them for palliative care purposes.

In January 2017, high-strength long-acting opioids were moved to the Palliative Care Facilitated Access (PCFA) mechanism. Lower-strength, long-acting opioids continue to be funded under the ODB program. Previously, the PCFA mechanism enabled access to a number of medications for a restricted number of physicians. We are working collaboratively with our partners, including the OPDP, to move several products from the PCFA drug list and to the ODB formulary. These changes will enable all prescribers and patients in Ontario to have access to these medications for palliative care purposes. Importantly, these changes will help increase access to quality hospice palliative care for patients across Ontario.

Once the transition process is complete, the criteria for registration as a PCFA prescriber will also change in order to ensure appropriate prescribing.

## ONTARIO SNAPSHOT

### Physician home visits



■ Last year  
■ Last 30 days

**20%** of decedents received one or more physician home visits in their last 30 days of life (excluding those who were institutionalized during that time period).

Physicians who will no longer meet the criteria will still be able to access these drugs through the ODB’s Exceptional Access Program Telephone Request Service, if the request meets specified criteria.

Our partnership with the Ministry and the OMA has yielded a more open process so that patients can receive these medications in a timely manner,” says Dr. Jakda. “For the first time, these medications are becoming readily available to prescribe by any physician in the province who would like to provide palliative care. This partnership and initiative have yielded higher access, greater cross-physician integration, and a model of care that will increase primary level palliative care.”

**The OPCN in Action:**

# Clinical Leadership and Palliative Care Quality Standard Update

With the launch of the OPCN last year, the province established a formalized provincial network with clear accountability to drive the delivery of quality coordinated hospice palliative care.

In our inaugural year, the Clinical Advisory Council (CAC) has been helping to support quality improvements on a number of fronts. Accountable to the OPCN Executive Oversight, the CAC provides recommendations on clinical improvements in hospice palliative care as well as advice on the clinical implications of any policy changes, all the while keeping patients and families at the centre of our purpose.

One key piece of work this past year has been the development of a Palliative Care Quality Standard, based on the best available evidence, which will elucidate the care we should all expect in our province.

“Our goal is to develop a quality standard that will give people an idea of what quality palliative care looks like, regardless of care setting,” says Melody Boyd, former OPCN Provincial Clinical Co-Lead. Along with our other Provincial Clinical Co-Lead, Dr. Ahmed Jakda, Ms. Boyd and the Secretariat worked with Health Quality Ontario to establish a Palliative Care Quality Standard Working Group. The Working Group includes 26 multidisciplinary clinicians, administrators, patients and families, with representation from all regions in Ontario and across healthcare sectors.

To date, the Working Group has finalized a list of priority topic areas, and has reached consensus on a set of quality statements. Each quality statement will be accompanied by indicators that can be used to measure improvements province-wide, as well as a plain language summary for patients and caregivers.

**ONTARIO SNAPSHOT**

## Patients receiving home care services\*

Last year of life



Last 30 days of life



■ Palliative Home Care (SRC 95)  
■ Other Home Care

**69%** of decedents received some home care in their last year of life (excluding those who were institutionalized during that time period).

\* Numbers may not add up due to rounding

In other work, the CAC has engaged a broad group of provincial stakeholders to discuss hospice palliative care as it relates to medical assistance in dying. “The need to understand palliative care and its benefits has increased with the developments in medical assistance in dying. It is important to explore how our palliative care system can continue to provide high-quality care and touch all patients who are suffering,” says Dr. Jakda. The OPCN has developed key messaging regarding medical assistance in dying to provide guidance to RPCNs on this issue as it relates to hospice palliative care.

“Quality standards are instrumental for supporting improvements in health care outcomes, health care processes, and ensuring patients, clients and families receive the best care possible. The palliative care quality standard recommendations are a result of the collaboration between clinicians, providers, patients and families. This engaged group of people deserve our recognition as they are helping to shape the future of palliative care in Ontario into one that is even more patient-focused, equitable, accessible, and sustainable.”

Ralph Ganter, CEO, Erie St. Clair LHIN

We are also supporting the roll-out of several initiatives to improve hospice palliative care in the province for the most vulnerable among us, including individuals who are homeless or vulnerably housed. In addition, we have initiatives targeting the needs of the First Nations, Inuit and Métis communities. With the predicted increase in life expectancy of many individuals living with chronic and terminal illnesses, palliative care is a key health service. Evidence suggests that initiating palliative care early can lead to better quality of life and longer lifespan. The development of initiatives that address the palliative care needs of specific populations through cross-sector partnerships, strengthening palliative care education for healthcare providers and leveraging low threshold strategies will all contribute to an improvement in the provision of hospice palliative care for all patients and will address disparities that currently exist.

We have partnered with the Ontario Telemedicine Network (OTN) to support and create innovative technology solutions to improve hospice palliative care, supporting successful regions with unique ideas in a climate ready for change. The utilization of technology and real-time connections will improve access to palliative care services, thereby improving clinical outcomes and increasing patient/family satisfaction. Technology solutions can also reduce travel time and reduce the cost of care while increasing efficiencies through improved management of chronic illnesses and timely access to palliative healthcare providers.

In addition, the Clinical Advisory Council has been exploring the current funding model to understand barriers and identify opportunities to evolve it to encourage a person-centred approach. “There is appetite for partners to look at this issue closely, and produce recommendations that would rectify the current palliative Alternative Funding Plan,” says Dr. Jakda, adding that the council has met with CCO, regional contacts and palliative care physicians to understand opportunities for moving this issue forward.

## Working with our clinicians

We are engaging with our clinical network partners on multiple initiatives.

### **IN PARTNERSHIP WITH THE NETWORK, THE CLINICAL ADVISORY COUNCIL IS:**

- Developing a provincial palliative care education framework
- Developing symptom management guidelines
- Defining palliative models of care
- Incorporating palliative content in Health Links Coordinated Care Plans
- Providing mentorship to Ministry-funded projects for vulnerably housed/homeless individuals
- Supporting the spread of the INTEGRATE project (which involves the earlier identification and management of patients who could benefit from a palliative approach to care)
- Providing leadership to identify innovative tele-palliative care projects with the Ontario Telemedicine Network
- Co-chairing the development of Palliative Care Quality Standard

### **ADVISING ON:**

- Federal funding opportunity for home and community care
- Access to opioids for palliative care purposes
- Medical assistance in dying
- Physician reimbursement funding
- Educational requirements for healthcare providers

## The OPCN in Action:

# Regional Engagement

Our collaboration with regions is critical to advancing high-quality, high-value person-centred hospice palliative care across Ontario. Thus, a key priority in our inaugural year was to work closely with the LHINs to evolve (or where necessary create) 14 RPCNs and ensure their governance structures align with the new direction under the OPCN.

As of our one-year anniversary, all LHINs had an RPCN director or lead in place and had hired part-time regional multidisciplinary clinical co-leads (for which the OPCN provided funding). The RPCN director and the clinical co-leads serve as important channels to share best practices and hear about ongoing barriers that clinicians may be facing in their regions.

Our consultations with LHIN CEOs and CCO Regional Vice-Presidents and CCO highlighted three key themes:

- Progress with governance structures are important but we have to acknowledge the variations within the LHINs.
- The work of the OPCN must be aligned with key Ministry initiatives, including *Patients First* and Health Links.
- Clear deliverables that everyone can work towards need to be outlined.

"In every LHIN, at every level, we saw the same passion and desire to provide excellent, accessible palliative care," says Angelika Gollnow, Director, the OPCN Secretariat. This valuable information from the consultations was consolidated into a document and shared with the LHINs.

## ONTARIO SNAPSHOT

### Palliative Care Beds

#### # Beds

##### Dedicated Beds

RH 298

Acute 239

CCC 472

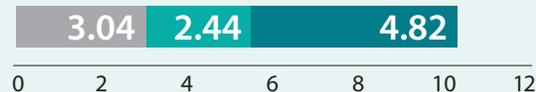
##### Non-Dedicated Beds

Acute 117

CCC 29

The numbers reflected here are a point in time capture of beds, as of March 2017.

#### # Beds per 1,000 decedents



- Residential Hospice (RH)
- Acute Care (PCU, dedicated)
- CCC (PCU, dedicated)

While the ratio of dedicated palliative care beds (PCU) to decedents is variable across the LHINs, provincially there were 3.1 residential hospice (RH), 2.4 acute care, and 5.0 complex continuing care (CCC) beds per 1,000 decedents, according to the OPCN Regional Capacity Planning Survey conducted in December 2016.

There were an additional 18 pediatric residential hospice beds in Ontario.

## Supporting the Regions – Year One Highlights

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**14 Regional Palliative Care Networks** formed

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A **physician** and a **multidisciplinary clinical co-lead** hired for each LHIN, totaling **28 Regional Palliative Multidisciplinary Clinical Co-Leads**

More than **300 attendees** from the across the 14 LHINs participated in consultations; a Regional Engagement Summary was shared with the LHINs

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**Two-day regional leadership development** event held in March

**Bi-monthly teleconferences** held with Regional Palliative Multidisciplinary Clinical Co-Leads and the OPCN Secretariat

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**Bi-monthly teleconferences** held with Regional Palliative Care Network Directors and LHIN leads, and the OPCN Secretariat



“The Regional Palliative Care Networks are the implementation arm of the OPCN. As they develop and implement their local work plans and introduce new initiatives on the ground, they will make a real difference in the lives of patients and their families.”

**Dr. Robin McLeod**, Vice-President, Clinical Programs and Quality Initiatives, CCO  
Member, OPCN Executive Oversight

## The OPCN in Action:

# Regional Impacts

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All across Ontario, the RPCNs have been working with local healthcare professionals, stakeholders, patients and families to develop and implement initiatives that align with the OPCN priorities and meet the needs of their communities. Here are a few examples of the great work being done in the LHINs.

### Erie St. Clair: Focus on education

Each year, the Erie St. Clair Hospice Palliative Care Education Collaborative supports 15 to 20 education projects for healthcare providers and volunteers working in palliative care in the LHINs. The Collaborative works with partners from all sectors and settings to develop and deliver education based on national frameworks, tools, standards and best practices. The relationships formed through these projects and the ability to pilot work in one area and then use it another has enabled the LHINs to leverage scarce resources and improve palliative care across all sectors (e.g., community, acute care, long-term care) and healthcare roles (e.g., registered nurses, personal support workers, volunteers, etc.) throughout the LHINs.

“Patients often move through different care settings, so it is important to develop a common frame of reference for all settings and all professionals,” says Maura Purdon, Hospice Palliative Network Director and Cross Sector Education with Erie St. Clair. “At the same time, the content has to be relevant to the care providers, the setting and their patients.” She explains that the Collaborative facilitates the delivery of customized palliative care education as well as enables partners to offer programs such as Fundamentals, and Learning Essential Approaches to Palliative Care where existing resources may be insufficient to support delivery.

“One of the principles underpinning all of our projects has been an ongoing strong commitment to work in partnership and to share resources.”

**Maura Purdon, Erie St. Clair Hospice Palliative Network Director and Cross Sector Education**

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Recent pilot projects include:

- supporting professionals who often interact with the hospice palliative care system but usually receive limited entry-to-practice education in this area, including pharmacists, emergency medical services providers and police;
- providing palliative care information to personal support workers who assist clients with intellectual disabilities; and
- working with First Nations partners to develop culturally relevant training for healthcare professionals.

“These projects have been as much about relationship building as delivering education,” says Purdon.

## Central RPCN: Consulting with patients and providers

Before the launch of the OPCN last spring, the Central LHIN was already two years into a three-year action plan to improve palliative care services in the LHINs. A key component of the planning process has been to consult with those who are directly impacted by and involved with palliative care, asking for their insights about gaps in services and strategies for improvements.

The creation of a LHIN-wide, single-number crisis line is an example of an initiative born out of those consultations. “Patients and families told us that they had long lists of phone numbers to call if they needed help — doctors, nursing agencies, Community Care Access Centres (CCAC) — but in times of crisis they would get confused or frustrated and often ended up just going to emergency,” says Dr. Cindy So, the OPCN Regional Clinical Co-Lead for the Central LHIN.

The idea for a crisis line was not novel, but working out the logistics required input from a multidisciplinary working group that included expertise from community hospice teams, CCACs, educators, primary care and palliative care specialists, as well as from patients and family advisors. Contracting with a telehealth company, the LHINs launched a 24/7 palliative care crisis line 18 months ago (in late 2016). Now, patients and families across the LHINs can call one number and in less than two minutes be connected with a nurse trained in palliative care. Patients are identified through the LHIN (formerly the CCAC) so that their files can be transferred to the crisis line, allowing the nurse to triage patients to the most appropriate member of their care team.

**“I think everyone in the palliative care community sees room for improvement. Real change starts with good communication and a common purpose.”**

**Dr. Cindy So, the OPCN Regional Clinical Co-Lead for the Central LHIN**

“Some patients have given us feedback that the support of the crisis line helped them avoid a visit to the Emergency Department,” says Dr. So. “We are now evaluating the pilot and looking at how we can further improve the crisis line.”

An update about the crisis line was on the agenda of a recent full-day Palliative Care Summit held by the Central RPCN. More than 140 participants (representing primary, palliative, community and hospice care, as well as other sectors such as social work and ethics) took part in discussions about service needs and gaps at all stages of the patient journey.

In addition to updates about initiatives under the LHIN's three-year action plan, the day included education sessions on topics such as medical assistance in dying, spiritual care, the role of cannabis in palliative care, and complementary therapies.

“The summit was about giving and receiving information, and building a stronger community of practice within the region by creating linkages among various palliative care providers and sectors,” says Dr. So. “Our palliative care community is a very passionate group. Across all professions and settings, I see an incredible willingness to give their time and effort to improving palliative care for patients and families.”

## ONTARIO SNAPSHOT

### Unplanned Emergency Department Visits

% Patients with ED Visits

84%

56%

Total ED Visits

3.2

1.9

■ Last year  
■ Last 30 days

More than half of decedents had one or more unplanned visit to the Emergency Department (ED) visits in their last 30 days of life.

# Looking Ahead

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In our first year, we made significant progress in laying the ground work to improve the provision of person-centred, quality hospice palliative care for all Ontarians regardless of their age or disease type.



Both provincial and regional governance structures are now in place, the RPCNs are established, and the Executive Oversight and all Advisory Councils are fully functional. And we have already begun delivering on some of our initial work streams, such as sharing a current state assessment through a Summary of Findings slide deck and Regional Profiles tool.

Now, with a solid foundation at our feet, we are setting on the path to working together to transform hospice palliative care in Ontario. This fall, we will finalize our Three-Year Action Plan, which will establish our core priorities through to 2020.

The *Declaration of Partnership* and the 2014 Auditor General of Ontario Report, along with results of the regional leadership consultations, are providing key input in the preparation of the Action Plan. From the hundreds of recommendations put forward, the following major themes have emerged: coordination of services; communication among healthcare providers and with patients; improved and equitable access to services; education for healthcare providers, patients/families and the public; access to palliative care services within long-term care facilities; funding; primary care challenges; patient/caregiver support; and cultural competencies.

The Three-Year Action Plan will distill these recommendations into a tactical document, enabling regions to understand where we are headed and ensuring common understanding of which OPCN partners are leading action items. In addition, the Action Plan will address the importance of cultural competencies.

We will also develop a scorecard that supports performance measurement activities based on the priorities outlined in the Action Plan.

In the coming years, we will continue to grow and strengthen as a network, one in which programs and stakeholders will be more aligned, quality and performance will be measured, and patients and families will be at the centre of all that we do.

## EXECUTIVE OVERSIGHT MEMBERSHIP

### MEMBERS

#### Bill MacLeod

CEO, Mississauga Halton LHIN  
Co-Chair

#### Michael Sherar

President & CEO, CCO  
Co-Chair

#### Ralph Ganter

CEO, Erie St Clair LHIN

#### Dr. Robin McLeod

Vice President, Clinical Programs  
and Quality Initiatives, CCO

#### Dr. Joshua Tepper

President & CEO,  
Health Quality Ontario

#### Lee Fairclough

Vice President, Quality Improvement,  
Health Quality Ontario

#### Rick Firth

Co-Chair, Quality Hospice Palliative  
Care Coalition of Ontario and President  
& CEO, Hospice Palliative Care Ontario

#### Barb LeBlanc

Executive Director, Health Policy,  
Ontario Medical Association

## CLINICAL ADVISORY COUNCIL MEMBERSHIP

### MEMBERS

#### Dr. Ahmed Jakda

Provincial Clinical Co-Lead, OPCN  
Co-Chair

#### Melody Boyd, BScN, RN, MSc, MN

Provincial Clinical Co-Lead, OPCN  
Co-Chair

#### Robin Cano, RN

North West

#### Dr. Darren Cargill

Erie St. Clair

#### Dr. James Downar

Toronto Central

#### Dr. Russell Goldman

Toronto Central

#### Elan Graves, RN

Champlain

#### Dr. Deb Harrold

North Simcoe Muskoka

#### Tracey Human, RN

Central East

#### Jill Marcella, SW

North West

#### Robert Parke, SW/Ethicist

Central

#### Dr. Adam Rapoport

Toronto Central

#### Dr. Robert Sauls

Mississauga Halton/Central West

#### Dr. Joshua Shadd

Hamilton Niagara Haldimand Brant

#### Cindy Shobbrook, NP

Waterloo Wellington

#### Dr. Kirsten Wentlandt

Toronto Central

## DATA AND INFORMATION ADVISORY COUNCIL MEMBERSHIP

### MEMBERS

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Analytics and Informatics, CCO  
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#### Anna Greenberg

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Ontario Palliative Care Network

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OntarioMD

#### Cathy Lumsden

Health Shared Services Ontario

#### Jennifer Osesky

Sault Ste. Marie Health Links

#### Hsien Seow

Institute for Clinical Evaluative Sciences  
and McMaster University

#### Dr. Peter Tanuseputro

Bruyere Research Institute, Institute for  
Clinical Evaluative Sciences, and  
Ottawa Hospital Research Institute

#### Dr. Lisa Barbera

Sunnybrook Research Institute and  
Odette Cancer Centre

#### John Hirdes

University of Waterloo

#### Michael Hillmer

Ministry of Health and Long-Term Care

#### Ashif Damji

Ministry of Health and Long-Term Care

#### Caroline Heick

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#### Dr. Robert Fowler

Institute for Clinical Evaluative  
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#### Heather White

South West LHIN

## IMPLEMENTATION ADVISORY COUNCIL MEMBERSHIP

### MEMBERS

#### Chantell Tunney

Senior Director,  
Planning, Integration & Community  
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#### Brenda Carter

Regional Vice President,  
South East Regional Cancer Program  
Co-Chair

#### Kim Delahunt

Central West LHIN

#### Monica Staley

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#### Dr. Ahmed Jakda

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#### Melody Boyd, BScN, RN, MSc, MN

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#### Emmi Perkins

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#### Margaret Paan

Central West Palliative Care Network

## EX OFFICIO MEMBERS

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#### Lorri Eckler

Health Quality Ontario

#### Dr. Darren Larsen

OntarioMD

#### Jennifer Osesky

Sault Ste. Marie Health Links

## PARTNERSHIP ADVISORY COUNCIL MEMBERSHIP

### MEMBERS

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Care Coalition of Ontario and  
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Chair

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Executive Director, Health Policy,  
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Chair Alternate

#### Kathryn McCulloch

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#### Nancy Cooper

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#### Joanne DiNardo/Kelly Gorman

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#### Doris Grinspun

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#### Lisa Levin

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#### Kathryn Pilkington

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#### Christine Bigelow

Palliative Care Consultants Network

#### Natalie Gierman

Heart & Stroke Foundation of Ontario

#### Sue VanderBent

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#### Hsien Seow

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#### Mary Lou Kelley

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#### Rose Cook

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Erie St. Clair LHIN

Membership lists as of March 31, 2017.

Ontario Snapshots Source: The Ontario Palliative Care Network, Current State Assessment of Palliative Care Service Use: Summary of Findings. April 2017.

Decedents refers to patients who died in Ontario between April 1, 2014 and March 31, 2015.

# Ontario Palliative Care Network

