



# PALLIATIVE CARE IN THE COMMUNITY: AN ENVIRONMENTAL SCAN OF FRAMEWORKS AND INDICATORS JUNE 2013

AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE



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Prepared for: Canadian Hospice Palliative Care Association  
Prepared by: Dale McMurchy and Monica Aggarwal

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## INTRODUCTION

The most commonly accepted definition of “palliative care” is the one articulated by the World Health Organization (WHO):

*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

The Canadian Hospice Palliative Care Association (2011) defines “hospice palliative care” as: “whole-person health care that aims to relieve suffering and improve the quality of living and dying.” The purpose of hospice palliative care is to help patients and families: address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; prepare for and manage the dying process; and cope with loss and grief during the illness and bereavement. “Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-limiting illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care” (CHPCA 2011).

This report is part of a national initiative entitled *The Way Forward* which aims to 1) promote community-integrated palliative care by changing the understanding of and approaches to chronic, serious and life-limiting illness and dying, palliative and end-of-life care, and advance care planning, and 2) developing a National Framework to support improved integration. The initiative aims to enable better access to palliative care and to identify ways to involve providers earlier in the continuum of care to improve quality of life and reduce suffering through better integration of hospice palliative and end-of-life care within the health care system, including hospitals, long-term/continuing care, residential hospices, shelters and individual homes. Improved integration would also mean that all health care professionals could provide a palliative approach to care, supported by specialists palliative care when necessary. The initiative is funded by the Government of Canada from 2012-2015, guided by the Quality End-of-Life Care Coalition of Canada, and managed by the Canadian Hospice Palliative Care Association.

As part of *The Way Forward* initiative, this report provides the results of international and national environmental scans. The report commences with the results of a review of the international literature on palliative care quality initiatives and measures. It documents quality frameworks, standards, measures, indicators and instruments being used internationally to support the delivery of palliative care in the community (e.g., nursing homes, long-term care facilities, primary care, hospices, community palliative care programs).

The international literature review is followed by a national environmental scan of how palliative care is delivered in Canada and the information that exists at the local, provincial/territorial and national level in order to identify tools, indicators and the supporting data currently being used for palliative care. Note that this scan, while it includes all provinces and territories, is not comprehensive and may not include local examples of quality palliative care delivery at the community level. The objective is to provide jurisdictions with a summary of how palliative care is delivered in Canada and the type of information currently collected that could potentially inform local reform initiatives and support the development of local or national performance frameworks.

This environmental scan was conducted by completing a literature review of published evidence and grey literature and 25 key informant or group interviews with representatives from the provinces and territories, as well as interviews with representatives from selected regions or health sectors. Published evidence was retrieved from computerized bibliographic databases between the period 1996 and 2012 from Medline, PsycINFO, EMBAS and CINAHL. Searches involved combining key words such as: "palliative care," "hospice palliative care," "community palliative care," and "end-of-life care" with "quality indicators," "quality measures," "quality improvement," and "quality frameworks." The same searches were completed in the 'Google' search engine to retrieve key governmental and organizational reports.

This section presents the results of the literature review on palliative care quality initiatives and measures, including quality frameworks and indicators used internationally to support the delivery of palliative care services.

### 2.1 EUROPE: QUALITY INITIATIVES IN PALLIATIVE CARE

#### United Kingdom

##### **GOLD STANDARD FRAMEWORK**

In the United Kingdom, there are a number of quality improvement initiatives in place to address palliative care. These initiatives have involved the establishment of quality frameworks, standards, measures, indicators and instruments.

The Gold Standard Framework (GSF) is identified as a prominent and popular framework for delivering high quality palliative care. The GSF was initially developed to improve palliative care in primary care settings in 2000 (Gold Standard Framework, 2012). The framework includes the following dimensions (Hansford, 2007):

**Communication:** A palliative care register is created by the primary care team or individual care home, which includes information on patients identified as having end-of-life care needs. The register records information on the advanced care plan for the patient and the ongoing care delivered to the patient.

*Preferred Priorities for Care* is an instrument that is used to document the preferences of patients. It establishes an advanced care plan that allows the patient and their caregivers to plan and ensure that everyone involved in the patient's care knows his/her wishes (For more information refer to:

<http://www.endoflifecare.nhs.uk/tools/core-tools/preferredprioritiesforcare>) (NHS, National End-of-life Programme, 2013).

**Coordination:** A coordinator is designated with responsibility to oversee the implementation and maintenance of the framework for patients, families and caregivers.

**Control of Symptoms:** A patient's symptoms, problems and concerns (physical, psychological,

social, practical and spiritual) are assessed, recorded, discussed and acted upon, according to an agreed process. A proactive approach to prescribing is put in place, particularly in after-hours' situations.

**Continuity:** All information is provided to all health care professionals involved in the care of the patient. This includes the use of an after-hours' handover form which provides information on; diagnosis, treatment, up-to-date medication, contact details of family/caregivers, and the views of the patient regarding care.

**Continued learning:** There is a commitment to learning about end-of-life care and developing action plans to meet learning needs. Specialist palliative care providers provide leadership in the delivery of this education. There is continuous assessment of care delivered to patients with a focus on achievements and areas of improvement.

**Caregiver support:** The needs of caregivers' are assessed and supported. This includes: emotional support (caregivers are listened to, kept informed and encouraged to play a significant role in the patient's care based on a mutual understanding); practical hands-on support (e.g. provision of a night nurse, respite care, day hospice, equipment, etc.); and bereavement support (e.g., developing a bereavement protocol).

**Care in the dying phase:** Patients in the last days of life are cared for appropriately through the GSF minimum protocol or by implementing the *Liverpool Care Pathway* (LCP). This includes: discontinuing non-essential interventions and drugs, considering comfort measures, psychological and religious/spiritual support, bereavement planning, communication and care after death.

The *GSF minimum protocol* is a checklist tool for care provided during this phase. It includes prompts for reviewing medications, notifying after-hours' health professionals and accessing the decided plan of care (For more information refer to:

[http://www.palliativecareggc.org.uk/uploads/file/education/glg/misc/C7\\_care\\_of\\_the\\_dying\\_GSF.pdf](http://www.palliativecareggc.org.uk/uploads/file/education/glg/misc/C7_care_of_the_dying_GSF.pdf) (Palliative Care Greater Glasgow, 2013).

The *Liverpool Care Pathway* provides information on best practices to support health professionals in systematically delivering all aspects of patient and family care in the last hours of a patient's life. (<http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/documentation-lcp/>) (Marie-Curie Palliative Care Institute, 2013).

In 2004, the GSF was adapted and piloted for use in care homes (e.g., nursing and residential homes). The Gold Standards Framework for Care Homes (GSFCH) provides similar templates and assessment tools as the GSF, with modifications relevant to the residential facility environment. Since 2006, the GSF has been adapted to address end-of-life care for other populations (children) and settings (prisons, acute and community hospitals) (GSK, 2012).

In 2008, the Department of Health in the United Kingdom launched the national strategy for End-of-life Care (Omega the National Association for End-of-life, 2009). The strategy focuses on providing high quality care in the final years of life by health and social services. The strategy outlines the pathway and approach to delivering palliative care which includes: identification of people approaching the end-of-life; assessment and agreement on how to meet people's needs and preferences through the use of advanced care planning; coordination of care; delivering high quality services in all locations; managing the last days of life; and supporting caregivers.

After the release of the national strategy, members of Strategic Health Authorities determined there was a need for a national approach to developing quality standards for care provided to people at the end-of-life (Department of Health, 2009). In response, the

Department of Health published a report on quality markers that align with the national strategy and GSF (Department of Health, 2009). The *quality markers* are designed for services (Primary Care Trusts (PCTs), Local Authorities (LA), and Strategic Health Authorities (SHAs)) responsible for executing end-of-life care services and for service providers to assess their progress in improving end-of-life care. Quality measures have been developed for all sectors including: primary care, acute hospitals, community hospitals, care homes, specialist palliative care, inpatient facilities (hospices), providers of specialist end-of-life care services in the community, district/community nursing services, ambulance services, and after-hours medical services.

Quality measures focus on: public awareness, strategic planning, identification, communication and care planning, coordination of care across organizations, availability of service, care in the last days of life, care in the days after death, workforce planning, and monitoring. Quality measures for service providers commonly focus on: developing strategies and plans, mechanisms to assess and document patient preferences, mechanisms to assess and document caregivers needs, use of multidisciplinary team meetings, communications with after-hours care, nomination of a key worker, awareness and actions regarding training needs, adopting care management pathways for dying, and collating information on quality of care for audit purposes (For list of quality markers refer to:

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_101684.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf)

In 2009, the government commissioned an evaluation of end-of-life in primary care settings. In total, 502 family practices participated in the study. The primary care practices used an online *After Death Analysis (ADA)* tool, an instrument that assesses care delivered against the key tasks of the GSF. This tool was re-developed after consultations with clinicians, commissioners, researchers and evaluators and refined to reflect

the components of the End-of-life Strategy (GSF, 2012). The ADA tool was deemed by participants in the study to be valuable in supporting improvements in the end-of-life care. The tool has also been adapted to the home care setting (For more information on the ADA Tool refer to: <http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/ADA%20Briefing%20paper.pdf>) (GSF, 2012). An assessment of primary care practices indicated that over 60 per cent of practices in the United Kingdom are using the GSF to improve palliative care (British Medical

Association and NHS Employers, 2011).

The Quality and Outcomes Framework (QOF) is a voluntary incentive scheme for primary care practices in the United Kingdom and is part of the General Medical Services Contract. The QOF includes groups of indicators, by which practices score points according to their level of achievement. The results for each practice are published annually. For palliative care, the following indicators are tracked by primary care practices (Table 1).

**Table 1.** Quality and Outcomes Framework Palliative Care Indicators in Primary Care

Domain	Indicator	Criteria
Records	The practice has a complete register available of all patients in need of palliative care/support irrespective of age	<ol style="list-style-type: none"> <li>1) Death of patient in the next 12 months can be reasonably predicted</li> <li>2) Patient has advanced or irreversible disease and clinical indicators of progressive deterioration (one core and one disease specific indicator in accordance with the GSF Prognostic Indicators Guidance (Refer to: <a href="http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20October%202011.pdf">http://www.goldstandardsframework.org.uk/Resources/Gold Standards Framework/General/Prognostic Indicator Guidance October 2011.pdf</a>) (GSF, 2012)</li> <li>3) Patient is entitled to a DS 1500 form - the form is designed to expedite the payment of financial benefits and can be issued when a patient is considered to be approaching the terminal stage of their illness. A terminally ill patient is defined as suffering from a progressive disease and is not expected to live longer than six months</li> </ol>
Verification	The practice reports the number of patients on its palliative care register	
On-going management	The practice has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed	A checklist can assist with ensuring all aspects of care are addressed. Tools include: supportive care register (SCR) templates from the GSF

### NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE (NICE)

The National Institute for Health and Clinical Excellence (NICE) has a quality standard used by service providers to ensure that systems are in place to identify people approaching end-of-life in a timely way (National Health Service, 2011). The quality standard applies to all settings and services in which care is provided to adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. The audience for this standard is health care professionals, commissioners, patients and families. The standard provides quality measures, indicators and instruments based on the following outlined quality statements:

**Identification:** People approaching the end-of-life are identified in a timely way.

**Communication and information:** People approaching the end-of-life and their families and caregivers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

**Assessment, care planning and review:** People approaching the end-of-life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalized care plan for current and future support and treatment.

**Holistic support – physical and psychological:** People approaching the end-of-life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

**Holistic Support – social, practical and emotional:** People approaching the end-of-life are offered timely personalized support for their social, practical and emotional needs, which is appropriate to their preferences, and maximizes independence and social participation for as long as possible.

**Holistic support – spiritual and religious:** People approaching the end-of-life are offered spiritual and religious support appropriate to their needs and preferences.

**Holistic Support – families and caregivers:** Families and caregivers of people approaching the end-of-life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

**Coordinated care:** People approaching the end-of-life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

**Urgent care:** People approaching the end-of-life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

**Specialist palliative care:** People approaching the end-of-life who may benefit from specialist palliative care are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

**Care in the last days of life:** People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalized care plan, including rapid access to holistic support, equipment and administration of medication.

**Care after death – care of the body:** The body of a person who has died is cared for in a culturally sensitive and dignified manner.

**Care after death – verification and certification:** Families and caregivers of people who have died receive timely verification and certification of the death.

**Care after death – bereavement support:** People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and

spiritual support appropriate to their needs and preferences.

**Workforce training:** Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end-of-life and their families and caregivers.

**Workforce planning:** Generalist and specialist services providing care for people approaching the end-of-life and their families and caregivers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

For these quality statements, the standard recommends using *measures* from the End-of-life Strategy (GSF, 2012). Quality measures have also been developed for spiritual support and bereavement care (Refer to: [http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/140771Draft\\_Spiritual\\_Support\\_and\\_Bereavement\\_Care\\_Quality\\_Markers\\_1.pdf](http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/140771Draft_Spiritual_Support_and_Bereavement_Care_Quality_Markers_1.pdf)) (NHS, National End-of-life Programme, 2011).

*Indicators* are recommended from the End-of-life Care Quality Assessment Tool (ELCQuA) (Refer to:

[http://www.elcqua.nhs.uk/documents/measures/eol\\_measures\\_car.pdf](http://www.elcqua.nhs.uk/documents/measures/eol_measures_car.pdf)) (NHS, National End-of-life Programme, 2013) and quality and national indicators (Refer to: <http://www.ic.nhs.uk/>) (NHS, 2013).

*Instruments* that are recommended for measurement include: Prognostic indicator guidance, supportive and palliative care indicator tool from NHS Scotland (Refer to:

<http://www.scotland.gov.uk/Resource/Doc/924/0111396.pdf>) (NHS Lothian, 2013); QOF Palliative Care Indicator, Office for National Statistics (ONS) National bereavement survey (VOICES); NICE cancer service guidance; 2011/12 Adult Social Care Outcome Framework; NHS inpatient services survey; and needs assessment pathway and holistic common assessment guidance from the National End-of-life Care Programme.

The Support Team Assessment Schedule (STAS) is a popular instrument for measuring palliative care outcomes. It is a unique tool that was developed in the United Kingdom to assess clinical outcomes and intermediate outcomes of palliative care. STAS is used to compare palliative care services or for clinical audits. It consists of nine core and up to 20 optional items that assess physical, psychosocial, spiritual, communication, planning, family concerns and service aspects (For access to the STAS tool refer to: <http://www.csi.kcl.ac.uk/tools.html>) (Kings College London, 2013).

### LIMITATION OF THE GOLD STANDARD FRAMEWORK

A limitation identified in the GSF is the lack of focus on the psychosocial care dimension (Oliver, 2010). This includes counselling for quality of life issues and providing cultural, religious and spiritual support to patients and families. A pilot study was done to develop quality indicators for psychosocial care in the community through a review of literature and consultations with experts. The instrument was pilot tested with six participants who worked with patients and families in the community and were part of a multidisciplinary team. The study found agreement on the following psychosocial domains and indicators (For more information refer to: [http://www.ajan.com.au/Vol27/27-3\\_Oliver.pdf](http://www.ajan.com.au/Vol27/27-3_Oliver.pdf)):

1. Professional practice
2. Communicating with patient and caregiver(s) on palliative care and end of life issues
3. Comfort and enhancing quality of life through symptom management
4. Effective counselling approaches consistent with quality of life issues
5. Ethical issues in palliative care
6. Advanced directive in palliative care
7. Cultural, religious and spiritual support for patient and family
8. Supporting patient, family and caregiver through grief, loss and bereavement
9. Care and support following death
10. Palliative care team support
11. Professional and personal development of palliative care team members
12. Evidence-based practice in palliative care

## Scotland

In response to recommendations by the Scottish Parliament Health and Sport Committee and the Living and Dying Well National Advisory Group, Healthcare Improvement Scotland was asked to develop indicators for palliative care (NHS Scotland, Healthcare Improvement Scotland, 2011). These indicators were developed by: reviewing the literature, documents and policies from the Scottish Government, expert opinion, and technical expertise on data sources (for nationally available palliative care data). This resulted in recommendations for four quality indicators:

1. **Identifying people with palliative and end-of-life care needs** – this indicator examines the number of patients that are on a palliative care register
2. **Assessment and care planning to meet patients' palliative and end-of-life care needs** – this indicator examines the total number of patients on the palliative care register with an electronic palliative care summary (ePCS). The ePCS captures information on anticipatory care plans (ACPs) which outline the patient's wishes

for treatment and care in the event of sudden deterioration. An ACP includes information on: medical diagnoses, the patient and caregiver's understanding of diagnosis and prognosis, patient wishes on preferred place of care, resuscitation (DNACPR) status, medication and equipment left in the patient's home "just in case," and current prescribed medication and allergies, in line with the emergency care summary (ECS)

3. **Accessing the anticipatory care plan (ACP) in all unscheduled care settings** – this indicator examines the number of individuals who have had their ePCS accessed at least once in an unscheduled care setting in the past 12 months
4. **Place of care at end-of-life** – this indicator examines the total bed days spent in an acute hospital setting in the six months before death for those people who died within a specified year. The purpose of the indicator is to assess whether the service is responding to the patient's preference of location of care towards their end-of-life

## Italy

In Italy, the National Health Authority commissioned the development of quality indicators for palliative care. This work resulted in the creation of 39 indicators, in which 12 (30%) indicators were based on structure, 25 (64%) indicators were based on process, and 2 (5%) indicators were based on outcomes (For specific indicators refer to:

<http://rd.springer.com/article/10.1007/s00520-011-1301-y>) (D'Angelo et al., 2012).

An Italian study conducted a comparative analysis

of this list with dimensions from the National Consensus Project for Quality Palliative Care in the United States (described below) and found that this list only addressed five dimensions (structure and process of care; physical aspects of care, psychological and psychiatric aspects of care; social aspect of care; care of the imminently dying patients) (D'Angelo et al., 2012). Indicators found missing were those for spiritual, religious and existential aspects of care; cultural aspects of care; and ethical and legal aspects of care.

### 2.2 UNITED STATES: QUALITY INITIATIVES IN PALLIATIVE CARE

#### **NATIONAL CONSENSUS PROJECT (NCP) FOR QUALITY PALLIATIVE CARE**

In 2001, a consortium of four national palliative care organizations formed the National Consensus Project (NCP) for Quality Palliative Care. This included the American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, and the National Hospice and Palliative Care Organization (National Consensus Project, National Quality Forum, 2013). The goal of the NCP was to create clinical practice guidelines to guide the expansion of palliative care in the United States. These guidelines would apply to the: consultation service team; dedicated inpatient unit; combined consultative service team and inpatient unit (hospital and nursing home); combined hospice program and palliative care program; hospital or private practice based outpatient clinic; hospice based palliative care at home; and hospice based consultation in outpatient settings. Patients are considered to be palliative if they have: congenital injuries or conditions, acute, serious and life-threatening illnesses, progressive chronic conditions, chronic and life-limiting injuries from accidents or other forms of trauma and seriously and terminally ill patients.

The NCP provides a framework with eight domains and preferred practices for each domain (National Consensus Project, National Quality Forum, 2013). The domains include: structure and process of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care, spiritual, religious and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical/legal aspects of care (See Appendix A).

#### **“PREPARE, EMBRACE, ATTEND, COMMUNICATE, EMPOWER”**

In 2008, the Centers for Medicare & Medicaid Services (CMS) made it mandatory for U.S. hospices to implement comprehensive quality improvement programs. CMS contracted with the

Quality Improvement Organization in North and South Carolina to develop quality measures and instruments to assess the quality of hospice and palliative care (Schenck 2010). This project was called the PEACE project, '(Prepare, Embrace, Attend, Communicate, Empower). The goal of the project was to complete a focused review of scientific literature and organizations to identify quality measures in alignment with the National Consensus Project that had been, or had the potential to be, used with patients in hospices or palliative care. A Technical Expert Panel rated quality measures on: importance, scientific soundness, feasibility and usability, using numeric scores for each dimension. The study identified 174 measures of which, 88 were determined appropriate to the setting. These measures were grouped by the domains of the NCP and focus primarily on processes of care rather than clinical outcomes and structures. 'Adverse events' is added as a domain to the framework. (For information on these quality indicators, instruments and specifications, refer to: <http://www.thecarolinascenter.org/default.aspx?pageid=46>) (The Carolinas Centre for Medical Excellence, 2013).

#### **INITIATIVE FOR PEDIATRIC PALLIATIVE CARE (IPPC)**

In the United States, the Initiative for Pediatric Palliative Care (IPPC) established nine goals and 41 indicators for six quality domains for children living with life-threatening conditions. These domains include: holistic care of the child; support of the family unit; relief of pain and other symptoms; grief and bereavement support (For specific indicators refer to: [http://www.ippcweb.org/domains\\_eap.pdf](http://www.ippcweb.org/domains_eap.pdf)) (Dokken 2002).

## 2.3 AUSTRALIA AND NEW ZEALAND: QUALITY INITIATIVES IN PALLIATIVE CARE

The Australian Government developed a national palliative care strategy and framework that focuses on: building awareness and understanding of palliative care by the community and health care professionals; continuous quality improvement and effectiveness of palliative care service delivery; and creating partnerships between health and social service providers to support the delivery of high quality palliative care (Australian Government, Australian Institute of Health and Welfare, 2007).

The strategy has been embedded in the requirements for palliative care within the Australian Health Care Agreements (AHCAs). Specifically, jurisdictions and the Australian Government are held responsible for improving the provision of palliative care services and implementing the National Palliative Care Strategy. The AHCAs also require states/territories to work collaboratively through defined information management governance arrangements to develop relevant performance indicators, including indicators for access to and quality of palliative care services (Australian Government, Australian Institute of Health and Welfare, 2007).

In 2003, the Palliative Care Intergovernmental Forum, which consisted of representatives from the state and territory governments and the Australian Government, agreed on four high-level national performance indicators that reflect the goals and objectives of the National Palliative Care Strategy (Australian Government, Australian Institute of Health and Welfare, 2007). These include:

At the regional level:

- The proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements.

At the agency level:

- The proportion of palliative care agencies,

within their setting of care that routinely undergo formal assessments against the Palliative Care Australia Standards. These are voluntary standards that describe the key dimensions for providing quality palliative care.

- The proportion of palliative care agencies, within their setting of care that actively collect feedback from clients and staff relating to services and service delivery.
- The proportion of palliative care agencies, within their setting of care that have formal working partnerships with other service provider(s) or organization(s).

National Standards have also been developed for providing quality palliative care in all settings (Palliative Care Australia, 2005) (See Appendix B). Palliative care is defined as: “care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life” (Palliative Care Australia, 2005). The term “life limiting illness” describes illnesses in which it is expected that death will be a direct consequence of the specified illness.

The Palliative Care Outcomes Collaboration (PCOC) is a national program in Australia that use standardized clinical assessment tools to measure and benchmark patient outcomes in palliative care (Australian Government, 2012). Four outcome measures are assessed: time from referral to first contact, time in unstable phase, change in pain, and change in symptoms relative to the baseline national average (X-CAS). The following clinical assessment tools are used: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status Scale (AKPS), and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) (For detailed information on indicators refer to: <http://ro.uow.edu.au/cgi/viewcontent.cgi?article=1151&context=ahsri>).

Clinical indicators have been identified for delivering palliative care at the practice level in Australia and New Zealand, which include:

identification of palliative patients and clinical indicators such as symptom management and pain screening, assessment and management

(Refer to:

<http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1320265764&sid=>) (Australia and New Zealand Society of Palliative Medicine, 2010).

This section summarizes the types of quality indicators and measurement tools identified in the international literature review.

### 3.1 QUALITY INDICATORS FOR PALLIATIVE CARE

Since palliative care is focused on providing quality of care to patients at the end-of life and their families, the implementation of quality frameworks and measurement of the quality of care through performance measures and indicators enables health care professionals, administrators and policy makers to monitor and improve palliative care. Quality indicators are defined as measureable items that focus on the outcomes, processes, and/or structures (Campbell 2003). Structural indicators include the attributes of the setting in which care is provided (e.g., material resources (facilities, equipment, and financing), human resources (number and qualifications of personnel), and organizational structure (e.g., methods of peer review, methods of reimbursement)). Process indicators represent the provision of care (e.g., practitioner's activities in making a diagnosis, recommending or implementing treatment). Outcome measures can describe the effects of care on the health status of patients and populations (e.g., physical decline, symptom management), patient and family experience (e.g., patient satisfaction) or impact on the health care system (e.g., length of stay, cost).

A systematic review was recently completed in Europe, which examined structural and process indicators for palliative care (Woitha 2012). The study was not setting or population specific. Authors completed a comprehensive review of the literature and expert consultations. This resulted in the identification of 110 quality indicators relevant to the palliative care setting. Quality indicators were grouped according to the following dimensions: definition of a palliative care service; access to palliative care; infrastructure; personnel palliative care services; documentation of clinical data; quality and safety issues; and reporting clinical activity of palliative care services. The majority of the 110 quality

indicators were process indicators (76) and some were structural indicators (34). Some of the indicators (24) were applicable only in specific settings: 10 in primary care, 13 in inpatient settings and one in home care. The other indicators were meant for all settings. (For specific information indicators refer to: <http://www.biomedcentral.com/imedia/1808206937840136/supp1.doc>) (Woitha 2012).

Another systematic review investigated and identified quality indicators (outcome, process and structures) for palliative care in all countries, patient groups and settings (Pasman 2009). Indicators were categorized based on the eight domains of the National Consensus Project for Quality Palliative Care in the United States. The review identified 142 overlapping quality indicators from 16 publications. The indicators covered five of the eight domains. There were no indicators for the cultural aspects of care. The majority of the indicators were process indicators. Many outcome indicators were found from one indicator set (Peruselli 1997) in which authors used two instruments (Support Team and Assessment Schedule (STAS) and the Therapy Impact Questionnaire (TIQ)). The results of the systematic review are as follows:

- **Structure and process of care domain:** 13 outcome indicators, 27 process indicators (e.g., communication and information with regard to prognosis and goals), 4 structure indicators
- **Physical Aspects of Care:** 26 outcome indicators, 20 process indicators (e.g., assessment of treatment and pain or dyspnea) and 0 structure indicators
- **Psychological and Psychiatric Aspects of Care:** 16 outcome indicators, 4 process indicators (e.g., anxiety or emotional support) and 0 structure indicators
- **Social Aspects of Care:** 2 outcome indicators, 4 process indicators and 0 structure indicators

- **Spiritual, Religious and Existential Aspects of Care:** 0 outcome indicators, 1 process indicators and 0 structure indicator
- **Cultural Aspects of Care:** None of any indicator
- **Care of the Imminently Dying Patient:** 0 outcome indicators, 10 process indicators and 2 structure indicator (e.g., aggressiveness of care and bereavement)
- **Ethical and Legal Aspects of Care:** 0 outcome indicators, 16 process indicators, 0 structure indicator (e.g., documentation of advanced care planning) (For specific indicators refer to: <http://nvl002.nivel.nl/postprint/PPpp3206.pdf>) (Pasman et al., 2009).

Another study examined which quality indicators are feasible and usable in all settings where palliative care is delivered to *adult patients* in the Netherlands (Claessen 2011). The first phase of the study involved a literature review that derived an inventory of relevant quality indicators. The study found most indicators were focused on: process or outcomes rather than structures; and physical care rather than social and spiritual aspects of palliative care. In the second phase, patients, relatives, and caregivers were consulted on the content of these indicators. This resulted in a new inventory of indicators, which were assessed and further revised based on expert consultations in the field. In the final phase, these indicators were tested in 14 organizations providing palliative care for feasibility and usability. The end result was the development of 33 indicators for patient care and 10 indicators for support to families before and/or after the patient's death. The quality domains concerning palliative care for patients included: management of pain and other physical symptoms, care for psychosocial well-being, care for spiritual well-being and general aspects. Quality indicators concerning support or aftercare for relatives included: care for psychosocial and spiritual well-being of relatives, general aspects, and aftercare. (Specific indicators for each domain can be found at: [3924\(11\)00051-0/fulltext\) \(Claessen 2011\).](http://www.jpsmjournal.com/article/S0885-</a></p></div><div data-bbox=)

A Canadian study examined and identified quality indicators for end-of-life care that were population-based and measurable using existing administrative health databases in Ontario and Nova Scotia (Grunfeld 2008). The end-of-life period was defined as a patient's final six months of life. The objective of the study was to assess the acceptability of identified indicators from the literature among stakeholder groups, including *cancer care* health professionals, patients, and family caregivers. Researchers identified 71 potential indicators based on previous work by various organizations, the research team, and a review of websites. Indicators focused on: access; care processes; satisfaction and communication; and physical, psychological, social, and spiritual well-being. After reviewing these indicators against data available in provincial databases, 19 quality indicators were identified. Stakeholders assessed these indicators for meaningfulness and importance, which resulted in 13 quality indicators (See Table 2). Lack of consensus on excluded indicators pertained to: patient preferences, knowledge of local resources and benchmarking.

**Table 2.** End-of-Life Indicators: Nova Scotia and Ontario

	Quality Indicator	Measurability	
		Nova Scotia	Ontario
1	Radiation therapy for uncontrolled bone pain for painful bone metastasis	P	N
2	Potent antiemetics for emetogenic chemotherapy	P	P
6	Frequency of Emergency Room visits	F	F
7	Intensive Care Unit days near the end-of-life	F	F
8a	Enrollment in palliative care within 6 months of death	P	N
8b	Enrollment in palliative care within 3 days of death	P	N
9	Multidisciplinary care	P	P
12b	Time and location of care (monthly visits)	F	F
14	Access to care	P	P
15	Access to palliative care assessments	P	N
16	Regular palliative care assessments	N	N
18	Advance care directives	N	N
19	Assessment of financial and caregiving resources	N	N

P= partially measureable, N=not measureable, F=fully measureable

#### 3.2 INSTRUMENTS/TOOLS FOR QUALITY IN PALLIATIVE CARE

A recent systematic review of instruments that have been used to complete outcome assessments for palliative care found that there were at least 528 different outcome assessment instruments (Stiel 2012). Instruments focused on 15 domains: quality of life, quality of care, symptoms and problems, performance status, psychological symptoms, decision-making and communication, place of death, stage of disease, mortality and survival, distress and wish to die, spirituality and personality, disease-specific outcomes, clinical features, meaning in life, and needs. The authors concluded that due to the vast number of instruments, there is no consensus on a universal set of instruments for outcome assessment in palliative care and that jurisdictions should focus on the development of a framework and determine corresponding instruments.

The Palliative Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) are instruments that measure outcomes in assessing the quality of care delivered to palliative care patients (Bausewein 2011). A study examined the literature to assess the use of these instruments in various settings. The results showed that POS was used in 43 studies and STAS was used in 39 studies. One study used both. These instruments were used for patients with cancer, HIV/AIDS and mixed groups. POS was also used for neurological, kidney, pulmonary and heart disease. Both tools were used for evaluation of care or interventions, description of symptom prevalence, and implementation of outcome measures in clinical practice. The study concluded that these instruments are well-accepted tools for outcome measurement in palliative care, both in clinical care and research.

Another study conducted a systematic review to investigate which instruments were most appropriate for measuring outcome measures for palliative care in long-term care (LTC) facilities (Parker 2010). This review focused on instruments which were reliable, valid and feasible, and identified ten outcome measures in which four

applied to residents in LTC facilities. The tools included Quality of Dying in Long-Term Care (QOD-LTC) and (QOD-LTC-C), Family Perceptions of end-of-life care (FPCS), End-of-Life in Dementia Scales (EOLD) and Palliative Outcomes Scale (POS). The remaining six instruments measured outcomes for residents in LTC facilities and other settings. This included: Family Assessment of Treatment at End-of-Life Survey (FATE), Toolkit – After-death Bereaved Family Member Interview, Quality of Dying and Death (QODD), The Quality-of-Life Concerns in End-of-Life Questionnaire (QOLC-E), End-of-Life Questionnaire (mQOLC-E) and RAI-PC. The authors concluded that the FPCS is the most suitable instrument for use in LTC facilities. The QOD-LTC scale and Toolkit Interview were most suitable for palliative care in residential aged care facilities.

Albers and colleagues (2010) conducted an inventory of all quality-of-life measurement instruments suitable for use in delivering palliative care. To assess the quality of these instruments, researchers examined their validity, internal consistency, reliability, responsiveness, and interpretability. The study identified 34 instruments that assess the 'quality-of-life' of palliative care patients (Table 3). The results of the study found that no instrument had satisfactory results for all measurement properties. Fourteen instruments received positive ratings for construct validity. Thirteen instruments were tested for reliability, but only two had positive results. Responsiveness was not tested adequately in any of the instruments. Few studies examined the interpretation of scores. Overall, the MQOL, followed by the QUAL-E and the QODD, received the best ratings for measurement properties. These instruments are used for a variety of purposes including: identifying cancer symptoms (Kirkova 2006), examining spiritual issues (Vivat 2008) and physical decline (Jardhoy 2007).

Table 3. Instruments for measuring QOL

BH1	EORTC QLQ-OES18	HQLI	MRDI
CAMPAS-R	EORTC QLQ-ST022	HQLI (in end stage cardiac disease patients)	MSAS
DS	ESAS	LCS	MASS (FC)
EFAT	FACIT-Pal	LEQ	CMSAS
EFAT-1	MQLS	<b>MQOL</b>	MSAS-GDI
Emanuel and Emanuel	Medical Directive	MQOL-CSF	SNI
<b>QUAL-E</b>	MVQOLI	NA-ACP	PAQ
<b>QODD</b>	MVQOLI-R	PDI	POS
PNPC	PNPC-sv		

This section summarizes how palliative care is delivered in Canada and provides some information on the tools, indicators and the supporting data currently being used for palliative at the local, provincial/territorial and national level. While information on each of the provinces and territories is presented, there may be gaps in the examples provided, especially at the local level.

### 4.1 NATIONAL: QUALITY INITIATIVES IN PALLIATIVE CARE

In Canada, improving the quality of end-of-life care gained momentum with the establishment of the Secretariat on Palliative and End-of-Life Care by Health Canada in 2002 (Health Canada 2007). This Secretariat formed five working groups, including the Best Practices and Quality Care Working Group (BPQCWG). This working group was responsible for coordinating activities related to best practices and quality care. In March 2002, the Canadian Hospice Palliative Care Association (CHPCA) published "A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice." In 2003, the BPQCWG collaborated with the Canadian Council on Health Services Accreditation (CCHSA) to develop an accreditation process (including national standards and measurement tools) for palliative end-of-life care (Health Canada 2007).

In 2006, the CHPCA in partnership with the Canadian Home Care Association (CHCA) developed a "gold standard" for four home care services: case management, nursing, palliative-specific pharmaceuticals and personal care at the end-of-life (For standards, refer to [http://www.chpca.net/media/7652/Gold\\_Standards\\_Palliative\\_Home\\_Care.pdf](http://www.chpca.net/media/7652/Gold_Standards_Palliative_Home_Care.pdf) (CHPCA and CHCA 2006). There is significant variation across Canada in the adoption of this standard and implementation of quality improvement initiatives for palliative care.

Accreditation Canada is an independent organization accredited by the International Society for Quality in Health Care (ISQua) that provides health care organizations in Canada with an external peer review process to assess and improve the health services based on standards of excellence. Clients include Regional Health Authorities, hospitals, and community-based programs and services from the private and public sectors. Accreditation standards assess

governance, leadership, infection prevention and control, and medication management, as well as the delivery of many types of health services.

*Accreditation Canada* has standards that related to palliative care in long-term care services and home care services, as well as separate standards for hospice, palliative and end-of-life care (HPEOLC) organizations and units:

<http://www.accreditation.ca/accreditation-programs/qmentum/standards/hospice-palliative-and-end-of-life-services/> The palliative care standards contain the sections: investing in hospice palliative and end-of-life services; engaging prepared and proactive staff; providing safe and appropriate services; enhancing quality of life; maintaining accessible and efficient clinical information systems; and measuring quality and achieving positive outcomes

There were indicators that were part of the HPEOLC program until May 2011. These indicators are not required, but some jurisdictions continue collect and use them. These indicators included:

- Percentage hospice palliative care services with 24/7 (24 hours per day, 7 days per week) access in-person and by telephone (with unique definitions for facility-based organizations and community-based organizations).
- Proportion of clients where a common pain assessment tool is used.
- Proportion of clients where a collaborative care plan is documented.
- Proportion of hospice palliative care clients that have an initial ESAS assessment within 24 hours and a week of admission (with unique definitions for facility-based and community-based organizations).
- Initial pain burden among hospice palliative care clients (with unique definitions for facility-based

and community-based organizations).

- Family/caregiver satisfaction scores from the FAMCARE scale, including information giving, availability of care, client's physical care, psychosocial care, and overall satisfaction
- Proportion of client records where client and family service goals are documented.

The Canadian Institute for Health Information (CIHI) has fostered the development of quality initiatives across the country. CIHI collects information which assists clinicians, managers, policy-makers and the public in understanding populations, planning, quality improvement, resources allocation and accountability (CIHI 2013). Currently, continuing care organizations (complex or chronic care hospitals, residential care facilities (e.g., long-term, nursing or personal care homes), and home care programs) across Canada are submitting data to CIHI's Home and Continuing Care (HCC) program. There is variation in the implementation and reporting of the results of the interRAI tools to CIHI across the country. In some jurisdiction data collection and reporting is mandatory, in others collection of these data is not widespread, and in others these tools are not used.

The Resident Assessment Instrument– Home Care (RAI-HC) assessment forms the foundation of the home care information collected by CIHI. The RAI-HC assessment tool covers the following four areas are specifically related to palliative care: goals of care, prognosis of less than six months to live, specialized treatments/therapies (including radiation and hospice care), and the Client Assessment Protocol (CAP). The RAI-HC tool collects information about long-stay home care clients' strengths, needs and preferences and enables the reporting of outcome scales (clinical and functional status), quality indicators, functional performance, cognition and mental health, clinical issues and social life (CAP) and resource utilization groups. Some indicators are relevant to palliative care (For detailed information refer to: [http://www.cihi.ca/CIHI-ext-portal/pdf/internet/RAI\\_MDS\\_SUPPORT2012\\_PDF\\_EN](http://www.cihi.ca/CIHI-ext-portal/pdf/internet/RAI_MDS_SUPPORT2012_PDF_EN)) (CIHI, 2013).

In addition, CIHI is collecting information from the interRAI Contact Assessment instrument (interRAI CA) which is used for home care intake from the community or hospital to screen vulnerable populations in hospital emergency departments (Refer to: [http://www.cihi.ca/CIHI-ext-portal/pdf/internet/HCRS\\_INFO2012\\_PDF\\_EN](http://www.cihi.ca/CIHI-ext-portal/pdf/internet/HCRS_INFO2012_PDF_EN)) (CIHI 2013).

The Resident Assessment Instrument–Minimum Data Set (RAI-MDS 2.0) forms the foundation of the continuing care information collected by CIHI. The RAI-MDS tool covers the same domains as the RAI-HC tool and also enables reporting of CAPs, outcomes scales, quality indicators and resource use, with indicators specific to those residing in continuing care (For detailed information refer to: [http://www.cihi.ca/CIHI-ext-portal/pdf/internet/CCRS\\_OVERVIEW2012\\_PDF\\_EN](http://www.cihi.ca/CIHI-ext-portal/pdf/internet/CCRS_OVERVIEW2012_PDF_EN)) (CIHI 2013).

There is also variation in the implementation of standardized symptom screening tools across Canada. In 2012, seven provinces were using a standardized tool for at least a proportion of patients where data are available at the provincial level. Providers in some provinces may be using such tools, but data are unavailable at the provincial level. The Edmonton Symptom Assessment System (ESAS) and the Palliative Performance Scale (PPSv2), along with the Canadian Problem Checklist are the most commonly used tools.

There are three Canadian initiatives underway to advance nursing-sensitive indicators: the Canadian National Nursing Quality Report (NNQR(C)); the Canadian Health Outcomes for Better Information and Care (C-HOBIC) program; and the Nursing Quality Indicators for Reporting and Evaluation (NQIRE) database launched by the Registered Nurses' Association of Ontario (RNAO). The initiatives focus on specific and complementary aspects of outcome measurement and aim to advance quality improvement in nursing based on standardized measurement. Indicators in one of more of the initiatives that could potentially related to palliative care include: nursing education, pressure ulcers and assessment, medication reconciliation, pain, functional status, falls, incontinence, dyspnea and nausea.

### 4.2 CANCER

Cancer has been relatively more organized as a set of programs in most jurisdictions compared to other disease categories and palliation overall. Nationally, and in most Canadian jurisdictions, there are frameworks and indicators for the delivery of palliative and end-of-life care for cancer patients. Most provinces report some cancer indicators on their cancer care websites. Many indicators relate to incidence, mortality, screening, access to care and patient volumes.

A 2007 literature review and environmental scan of the international literature funded by the Canadian Council on Health Services Accreditation found over 650 performance indicators related to cancer. Thereafter, 293 indicators were mapped to a conceptual framework of which 43 related to palliative care. Examples of palliative care indicators include: routine pain assessment in the last three days of life; timely change of pain management among outpatients and hospice patients with uncontrolled pain; radiotherapy for uncontrolled bone pain; collaboration with pain units; routine dyspnea assessment and treatment in the last week of life; routine spiritual assessment in expected dying; interval between last chemotherapy and death; location of death; frequency of emergency room visits (including within the last two weeks of life); number of hospital days near the end of life; rates of home care in the last six months; rates of physician home visits in the last two weeks of life; continuity of care provided by family physicians and non-family physicians; enrollment in a palliative care program; access to palliative care; existence of palliative care plans; number of staff trained in palliative care; number of palliative care units and beds; percentage of patients with advanced illness receiving opioids; and percentage of family physician practices that had implemented the Gold Standards Care Framework.

### CANADIAN PARTNERSHIP AGAINST CANCER (CPAC)

#### BACKGROUND

The Canadian Partnership Against Cancer (CPAC) is a federally-funded not-for-profit organization that supports improving cancer control across Canada. CPAC works with cancer experts, charitable organizations, governments, cancer agencies, national health organizations, patients, survivors and others to implement Canada's cancer control strategy. Its mandate covers the cancer control continuum, from prevention to survivorship and palliative and end-of-life care. Its priorities are prevention and screening, quality of care, system performance, knowledge management, improving the cancer journey, research, Aboriginal cancer control, and public engagement and outreach.

CPAC has supported advancing quality through the development of guidelines and standards, implementation of electronic tools to support best practices, and system performance monitoring. It has worked with cancer agencies and programs to identify a common set of indicators for system performance and the practices that lead to variability in outcomes. The System Performance Initiative is a collaboration with provincial cancer agencies and brings together some of the existing cancer-related data in Canada. It collects data from provincial registries, provincial cancer partners, and Statistics Canada and others.

CPAC will be launching a palliative care initiative, with a steering committee representing each province, to help establish best practices in palliative care.

#### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

The Partnership has released the 2009, 2010, 2011 and 2012 Cancer System Performance Reports. Over the years, the document has updated indicators and introduced new indicators for prevention, screening, treatment and long-term outcomes. The indicators related to the

patient experience in palliative care include:

- Screening for distress – seven provinces use standardized tools, mainly the ESAS and Canadian Problem Checklist (CPC)
- Patient satisfaction – Seven provinces have implemented the NRC Picker, Ambulatory Oncology Patient Satisfaction Survey (AOPSS) in hospitals. It covers the domains of physical comfort, respect for patient preferences, access to care, coordination and continuity, information and communication, and emotional support
- Place of death – Hospital versus other locations of death from Vital Statistics, Statistics Canada

## CANCER CARE ONTARIO

### BACKGROUND

Cancer Care Ontario (CCO) is an Ontario government agency that supports health service agencies with disease prevention and screening, access to care, the delivery of care and patient experience for cancer, as well as chronic kidney disease. CCO is involved in planning cancer services, contracting for services, building and maintaining information systems, developing guidelines and standards, and tracking and reporting performance. Its vision is that: Every person living in Ontario, when faced with a cancer diagnosis, should have the opportunity to: receive optimal symptom management; be supported with dignity and respect throughout the course of his/her illness; and in the face of incurable disease, each person should have the opportunity to live and die in a setting of his/her choice.

CCO's palliative care committee contributes to the provincial agenda for palliative care. The committee is composed of leads from each of the regions with the aim of having greater primary care and oncologist involvement. Currently, the committee is establishing a primary care strategy in which primary care providers and oncologists play a central role in the delivery of palliative care, with involvement and supported by specialist palliative care teams. There is currently

a working group to develop a lexicon for CCO which will include definitions for palliative and end of life. There is an effort to include discussions of palliative care earlier in the cancer care trajectory and include this approach within disease pathway definitions. For example, they have worked to map out disease pathways to ensure timely and appropriate access to the right treatment and care. The pathway integrates components of the Gold Standard Framework, including case finding, symptom assessment and care plans. Discussions of goals of care and advanced directive will be included under the pathway.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

Among the objectives for CCO, those most related to palliative care are: 1) the spread of standardized symptom screening and assessment tools (i.e., ESAS and PPS) to all cancer patients through the continued implementation of the Ontario Cancer Symptom Management Collaborative (OCSMC); 2) development of indicators to assess the quality of care; 3) development and implementation of a regional program model for palliative cancer care; 4) promoting regional partnerships; and 5) establishment of meaningful performance indicators for palliative care services.

For symptom and functional assessment, CCO promotes the use of the ESAS and the PPS. CCO uses ESAS in all regions, but the extent of its use varies by region and institution. These tools are available to patients on touch screen kiosks at the cancer centres, as well as online. These data go into a central database and can be linked with other patient data. ESAS and PPS data are looked at for threshold scores and at a population level for auditing, and tracking clinics, specific types of cancers and specific symptoms.

Some providers use the ECOG (Eastern Cooperative Oncology Group) tool for performance status in their clinics and recently a patient-reported version of ECOG was added to screening kiosks in cancer centres. This was done to ensure that performance status is used more consistently and to enable patients to have a

greater voice in their care plans. There is no standard measure for the client and family experience, although the FAMCARE and ambulatory oncology patient satisfaction survey (AOPSS) are used in some facilities.

CCO has been promoting symptom assessment and is working to link these with system indicators. The cancer scorecard includes:

- Symptom Assessment and Management – a) percentage of cancer patients screened (using the ESAS) at least once per month for symptom severity, b) percentage of patients who said their provider took their ESAS score into account, c) percentage of patients who said their physical and emotional symptoms were managed to a comfortable level, and d) percentage of patients who said their health care team talked with them about their ESAS.
- Percentage of patients who received chemotherapy in the last two weeks of life

- Percentage of patients who visited an emergency department in the last two weeks of life
- Percentage of patients who were admitted to an ICU in the last two weeks of life
- Percentage of patients who died in an acute care hospital
- Median length

CCO is working to further develop indicators and to have increasing participation throughout the health system, including primary care. This would be supported by infrastructure to collect and monitor indicators. Two new indicators under discussion include the percentage of patients referred to home care in last two or four weeks of life and the percentage of patients in cancer centres that are referred to palliative care clinics. There is also great interest in further developing further indicators for the primary care level.

### 4.3 BRITISH COLUMBIA: QUALITY INITIATIVES IN PALLIATIVE CARE

#### BACKGROUND

In British Columbia, palliative care services are provided by the five Regional Health Authorities (RHAs) and the Provincial Health Services Agency (PHSA). PHSA is responsible for managing provincial health-care programs and services related to end of life. RHAs have established a number of priority initiatives relating to palliative care and end-of-life programs.

British Columbia has 266 publicly subsidized hospice palliative care beds distributed across the province. PHSA also provides a range of end-of-life care services in several of its agencies. Hospice Societies provide many services that enhance the publicly subsidized services. Services are similar between regions, but can differ somewhat. Delivery may also vary between rural and urban areas. For example, in Fraser Health a team of palliative care specialist deliver hospice palliative care services in the home, hospital tertiary hospice palliative care units, residential care facilities and hospices based on a set of

Hospice Palliative Care Symptom Guidelines. Home care services for palliative care in the province fall under the Home and Community Care Policy Manual. Individuals of all ages at end of life have increased access to a range of home health services to help them stay at home as long as possible. The range of services include home support, community nursing, community rehabilitation, respite care, hospice care, and access to 24/7 information and support services.

In 2006, the Government of British Columbia published the *“Provincial Framework for End-of-Life Care”* containing more than 130 recommendations. This framework lays out the vision, principles and provincial policy on end of life care planning and services for health authorities and clients (British Columbia Ministry of Health 2006). The framework defines “end-of-life,” “palliative care” and “hospice care” as follows:

- *“End-of-life care* is the term used for the range of clinical and support services appropriate for

dying people and their families. The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying people and their families.”

- “*Palliative care* means the specialized care of people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term palliative care is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure.”
- “*Hospice palliative care* is a philosophy of care that stresses the relief of suffering and improvement of the quality of living and dying. It helps patients and families to: address physical, psychological, social, spiritual and practical issues and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; and cope with loss and grief during illness and bereavement.”

The provincial government implemented the Palliative Care Benefits Program (Plan P), which provides patients with terminal disease coverage for medications, medical supplies and equipment for care at home (UBC Centre for Health Services and Policy Research 2008). Distinctions between palliative care and end-of-life are not made for purposes of eligibility to the program. The provincial framework also provides guidance to family medicine, and in 2009 a palliative care incentive fee code was implemented for family physicians and a similar code was implemented for specialists in 2012.

A recent initiative has been the implementation of advance care planning to ensure that individuals have options for making their wishes and instructions for future health and personal planning known. Guidelines for advanced care planning have been released. As well, B.C. recently released the provincial *End-of-Life Care Action Plan* and established a provincial Centre of Excellence for End-of-Life, building on the expertise of Fraser Health Authority.

The province is currently working to develop an integrated framework for palliative care across the continuum of care that would include primary care, home and community care, residential care and acute care.

#### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

There are not palliative care registries at the provincial level; however some regions collect data at the local level. Four of the five RHAs are using the Continuing Care Information Management System (CCIM) to collect data (Quality End-of-Life Care Coalition of Canada 2008).

B.C. has a chronic disease registry maintained by the medical services plan. It collects data on chronic diseases based on whether or not they are on palliative care programs, ICD codes and data from vital statistics, such as number and percentage of natural deaths, cancer deaths, and non-cancer deaths in home, hospice, residential and hospital by RHA.

The RAI-HC and RAI-MDS assessment tools are used in B.C. (Quality End-of-Life Care Coalition of Canada 2008). It is mandatory for all regions to report these data to CIHI. This year B.C. will be receiving these aggregated data from CIHI. The Palliative Performance Scale (PPS) and ESAS assessments are used in some RHAs.

RHA program data may include: number of patients, services received, type of professional services received, type of non-professional services received, and costs. Home and Community Care data indicate type of services received, but cannot differentiate palliative clients.

As part of the recently released End-of-Life Action Plan, the province is looking at developing and reporting on key performance indicators.

### 4.4 ALBERTA: QUALITY INITIATIVES IN PALLIATIVE CARE

#### BACKGROUND

Palliative care services are delivered by Alberta Health Services (AHS), with programs and services varying across the five AHS zones. Typically services include support to patients, families and caregivers to manage the end-of-life and offer palliative assessments, exploring end-of-life care options, planning care at home, symptom assessment and management, and psychosocial support. Providers can include palliative nurses, physicians, dietitians, mental health therapists, pastors, pharmacists, rehabilitation therapists, social workers and volunteers (Alberta Health Services, 2013).

Each zone has some acute care palliative beds and hospice beds. Services are also delivered in the individual's home. Urban zones have dedicated palliative care home care teams that operate under home care regulations. Rural home care is typically organized more geographically with providers seeing a cross section of home care clients that may include palliative clients. Palliative care is also delivered in Health Centres and some zones have dedicated long-term care spaces for palliative care.

Palliative care consulting services are available across the province (by physicians, nurses or nurse practitioners) in person, on-call and/or via telehealth. These consulting services may cross the continuum of care. One zone has implemented an Advanced Care Planning and Goals of Care Policy and has staff dedicated to maintaining it who conduct audits and monitor whether directives are in place. The rollout of this policy is occurring across the other four zones with implementation across Alberta to be completed by the end of the coming fiscal year.

There is currently not a palliative care framework in Alberta, but a proposal to put a framework in place has been developed and is going forward for approval. In addition, the Government has established Continuing Care Health Service Standards that apply to palliative care clients receiving services in Continuing Care (Home

Living, Supportive Living or Facility Living) (Quality End-of-Life Care Coalition of Canada, 2008). Also Accreditation Canada and Canadian Hospice Palliative Care Association standards are applied.

Palliative patients are identified by referral, usually by a physician, but also from hospitals, cancer clinics and home care.

#### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

The Government of Alberta has mandated the use of the RAI-MDS in long-term care facilities and RAI-HC tools in supportive living and home care for long-term supportive and maintenance adult clients (Alberta Health Services 2011). However, the RAI-HC tool is not used for palliative or end-of-life patients. The RAI client assessment is being implemented as an intake and screening tool for home care, while the RAI Palliative Care (PC) assessment is being piloted in Calgary.

Increasing amounts of clinical information, including the RAI-HC, is being collected electronically but is not always available in aggregated form. RAI-MDS data are now being submitted to the Alberta Continuing Care Information System (ACCIS) and will eventually be submitted to the CIHI Continuing Care Reporting System. Submission of home care and supportive living program data to the ACCIS has begun and will later be fed into the CIHI home care reporting system.

The Edmonton Symptom Assessment System (revised version) (ESAS-R) is used in some zones, as is the PPS. Also used in some instances are: the Edmonton classification system for cancer pain (ECS-CP), Folstein mini-mental, CAGE, Palliative Outcome Scale, and internal tools.

Related to referrals some services may collect: the number of referrals, source of referral, resources used and client location. For access, one or more zones or services collect: the number of first visits, the number of follow-up visits, the number on the wait list, the length of time on the wait list, the time from referral to first contact and visit, the

percentage who died on the wait list, and the number of days in acute care waiting for hospice care.

The following are additional indicators collected by one or more zones or services: number of admissions, facility occupancy rates, case load, workload, number of consults, length of stay, number of transfers, number discharges, number of deaths, number of cancer deaths, goals of care designations in place, hospice preferences/choice, safety and incident reports, chart audits, staff education, and location of death.

The Edmonton Zone Palliative Care Program (EZPCP) is a community-based model designed to increase access to palliative care services in the most appropriate setting (Alberta Health Services 2012). The program focuses on shifting care from the acute care sector to the home and hospice palliative care units (in continuing or long-term care facilities) using an inter-professional service delivery approach. The program established the following performance domains and indicators for evaluation (Alberta Health Services 2012):

1. Financial performance: number of hours by provider, acute care beds saved per fiscal year, research produced, number of publications
2. Service quality: 24/7 access, continuity of care, average length of stay, service response time, occupancy rate, pain and symptom management, bereavement services and support, number of volunteers, training
3. Client and stakeholder satisfaction: number of physicians referring to program, reportable incidents, number of investigations
4. Employee satisfaction and learning: clinical education and skill development, article rounds, journal rounds, attendance at meetings, CPR re-certification
5. Professional practice: indicators for position descriptions, use of worker's compensation board and participation in WHMIS training (For specific indicators refer to:

[http://www.palliative.org/newpc/\\_pdfs/reports/Balance\\_scorecard\\_2010\\_to\\_2011.pdf](http://www.palliative.org/newpc/_pdfs/reports/Balance_scorecard_2010_to_2011.pdf) (Alberta Health Services 2012).

### 4.5 SASKATCHEWAN: QUALITY INITIATIVES IN PALLIATIVE CARE

#### BACKGROUND

The Government of Saskatchewan provides global funding to 13 RHAs to deliver health services that include palliative care services. Palliative care services are a component of Home Care Program, although palliative care services may also be delivered in various settings outside of home care.

A Provincial Palliative Care Steering Committee was established to address palliative care. This group represents all the health regions and includes those who work directly in or have direct responsibility for the delivery of palliative care in their regions and Ministry officials. This group continues to review policies relating to palliative care, palliative care tools, best practices, education for palliative care staff and palliative care data.

Palliative care may vary across the RHAs, the *Regina Qu'Appelle Health Region* has a multi-site palliative care program. The program falls under the regular Home Care Program but is focused solely on providing palliative care services. Services are provided to patients that have a progressive and terminal illness. These patients often have complex management issues (symptom, psychosocial issues) and are in the last three to six months of life. Most are cancer patients; however, the number of patients with chronic illnesses (end stage liver, heart or renal disease) is growing.

The program has a 9-bed tertiary acute care unit, partners with a 10-bed hospice, and cares for approximately 160-180 patients in home care settings. Physicians, coordinators, social workers, therapists spiritual care, nurses and trained volunteers deliver services to patients residing within a half hour radius of the city. Outside this radius, patients are supported by regular home care services. Palliative care physicians work on a consulting basis throughout southern Saskatchewan and manage patients who live in remote Saskatchewan communities where there is no physician readily available. The Palliative Care

program has partnered with the Salvation Army, which has a long-term care home and houses the Regina Wascana Grace Hospice (10 beds). The Salvation Army provides nursing staff and the palliative care program provides psychosocial staff and physicians.

Patients can move between sites (acute care; home care; hospice) and be followed by the same staff. The program also collaborates with Regina Palliative Care Inc. and the Greystone Bereavement Centre to provide extensive individual and group bereavement services including the Caring Hearts Camp for children who have experienced a death. A pain and symptom management clinic is offered by palliative care physicians in partnership with the Allan Blair Cancer Centre. The program places emphasis on education and training to patients/families and health care providers.

In Saskatchewan, palliative care refers to interdisciplinary services that provide active compassionate care to the client who is terminally ill at home, in hospital or in another care facility. It is available to terminally ill persons and their supporters who have determined that treatment for cure or prolongation of life is no longer the primary goal.

Currently, the Government of Saskatchewan does not have an overall provincial strategy for palliative care. The province has developed policy guidelines to assist RHAs deliver palliative care services which indicate: palliative care patients should die and live with dignity; palliative care services should focus on the terminally ill; the autonomy of the individual and family should be respected; and palliative education should be provided.

There is a Saskatchewan Home Care Policy Manual that outlines the policies and guidelines for the provision of palliative care in the home. The manual contains a definition and related stages of palliative care. It outlines dietary supplements and basic supplies for palliative patients, as well as what charges they are exempt

from. This Home Care Policy is mandatory throughout the province.

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#### **PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS**

Currently, there are no standardized provincial quality indicators for palliative care at the system or service delivery level. There is also no central palliative care registry to track patient care. Data

are collected by RHAs, but there is significant variation in the type of data collected.

At the provincial level, the Ministry of Health is collecting high-level information from the RHAs such as: number of palliative care clients, nursing units, palliative services, palliative meals, palliative home making services; number of palliative care clients; and number of services received.

RAI-HC and RAI-MDS assessments are being used in the home care and long-term care settings in all RHAs (except Athabasca region which is not using the MDS). These data are collected by RHAs and are available to the provincial government. In the acute care and home care settings, some service providers are also using the PPS. However, the information is not collated at the regional or provincial level. The palliative pain assessment tool and Wascana client-centred survey are used in some palliative care programs and the RAI-PC is being piloted. In all regions, service providers are involved in advanced care planning. However, this information is not being recorded in databases.

There is significant variation across the regions on the type of instruments that are being used. For example, the Cypress Hills Health Region is conducting a survey in long-term care facilities, which examines kindness, family experience and overall rating. The Saskatoon Region is completing a home care satisfaction survey. Prince Edward Parkland Health Region is conducting a patient experience survey in different settings and piloting the RAI PC assessment. Regional Health Authorities report the use of advanced care directives in all regions.

*The Regina Qu'Appelle Health Region Palliative Care Program* does not track quality indicators, such as patient satisfaction, symptom and pain management and outcomes. (Although they collected Accreditation Canada indicators in the past). The health region primarily captures administrative data such as: services delivered, location (at admission) and patient characteristics (diagnosis, gender). Physician claims databases

collect information on consultations. Home care databases (Procura) collect information on units of care (e.g., number of direct patient encounters or indirect care, such as charting). Patients in long-term care facilities are tracked if they are referred and registered with the palliative care program. The program faces challenges with respect to the lack of integration of patient information across sites. An initiative is underway to integrate the program's databases.

In Regina Qu'Appelle program, providers use the PPS and Palliative Pain Assessment tools, but the information is not being captured in databases. The PPS is linked to service delivery. The Wascana Client-Centred Care Survey (Palliative Care) (Asmundson 2002) has been administered by the program since 2001 to a sample of families 90 days after death through the mail. This survey examines satisfaction with physical care, emotional care, information and communication. Additional questions include: satisfaction with location of death and frequency and nature of bereavement follow-up. Historic data demonstrate high client satisfaction. Recent surveys have had a response rate of 40% and are used for quality improvement purposes. The program is seeking approval to use the FAMCARE tool, an instrument developed and validated for use in hospice palliative care populations. The program is also considering the use of the Bereavement Risk Assessment Tool (BRAT). This tool generates an acuity indicator, which examines the risk of a complicated bereavement. For the last year, the program has been collaborating with the Palliative Care Program in Winnipeg and St. John's Newfoundland to discuss experience with the tool. This tool is considered to be better than clinical judgment.

The program has not adopted the RAI-HC, RAI-PC or the Edmonton Symptom Assessment System (ESAS). They are waiting for the results of the RAI-PC pilot study in the Prince Albert Parkland Health Region. Currently, the palliative program is not collecting any information related to primary care.

## 4.6 MANITOBA: QUALITY INITIATIVES IN PALLIATIVE CARE

### BACKGROUND

The Government of Manitoba funds Regional Health Authorities (RHAs) to deliver services to palliative patients. Each region has health-care professionals designated to provide care to palliative patients within their jurisdiction. Palliative care is provided through acute care, long term care and community settings. Palliative care services have been expanded over time to include greater support at home.

The goal for provincial palliative care programs is to support a comfort-focused approach to care to maximize quality of life in the face of a terminal illness and to provide quality palliative care close to home. The province has a Provincial Palliative Care Drug Access program that provides coverage for medication costs.

Palliative care can vary across the RHAs, in the Winnipeg RHA services are provided under an administrative structure led by a medical director and program director. Under this structure, palliative patients can receive services from the palliative care team in any care setting (i.e., home, acute care or long term care). The region is divided into six catchment areas and each has a palliative care coordinator who is the case manager for each patient and community palliative care teams include palliative care physicians, palliative care clinical nurse specialists, psycho-social support, and palliative care community nurses. Direct care services are provided by the regional home care program. Palliative care teams are available to see patients who are formally registered in the palliative care program or at any stage during their illness through consultative services. A community palliative care nurse is available 24/7 to respond to urgent needs from palliative care patients at home. There are 45 acute palliative care beds (15 at St. Boniface Hospital and 30 at Riverview Health Centre) and 16 hospice beds. Admissions to all palliative care program beds are managed centrally by the program team.

There is a provincial palliative care network with

representatives from all regions that meets quarterly to share experiences, plan collaborative work and avoid duplication of processes. The network has developed a strategic plan to guide their activities. The network reviewed Accreditation Canada standards of care and CHPCA documents, including the norms of practice, and developed provincial Norms of Practice to guide service provision that are reviewed every four years.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

Currently, there are no provincial palliative care registries or formal indicators at the system or service delivery level that measure the quality of palliative care. Each RHA collects data on services delivered in their regions. These data are used for regional planning and program review and development and may include data based on the 2005 national norms for palliative care patients and Accreditation Canada practices, as well as information on: patients (e.g., age, gender), referrals, diagnosis, location of service, length of time in palliative program, location of death, number of patients consultations, and who provides the consultation and the reason. In the acute care sector, data are collected based on standards and can include the mean and median length of stay, admission from community and LTC, and discharge to home, other facility or death.

The Regional Health Authority Indicator Project entitled the "COGNOS tool" is developing a set of indicators (not exclusive to palliative care). This information will be aggregated at the provincial level. The long-term goal is to include indicators for palliative care.

Some instruments used at the service delivery level (in some regions) include: FAMCARE, PPS and ESAS. An example of information collected includes: percentage of Edmonton assessments, social assessments and palliative performance conducted; percentage with pain management at admission; bereavement assessment conducted;

client and family goals are documented; medication reconciliation at admission; presence of a collaborative care plan; and percentage of patients with 24/7 access. There is no collection of information on advance care plans or advance

directives, but some jurisdictions require and document resuscitation status at program admission. Some hospitals collected patient satisfaction data.

### 4.7 ONTARIO: QUALITY INITIATIVES IN PALLIATIVE CARE

#### BACKGROUND

In Ontario, palliative care services are delivered in hospitals, long-term care homes, residential hospices and individual homes. Community Care Access Centres (CCACs) are the prime delivery agents for home care for patients requiring palliative care. CCACs provide care coordination for patients based on their prognosis and care needs. CCACs contract with providers to offer services such as: in-home nursing, personal support, other services (e.g., occupational therapy, physiotherapy, social work, speech-language pathology, dietetic and pharmacy services). They also buy medical supplies, laboratory and diagnostic services, rent hospital and sickroom equipment, arrange transportation to other health services, and authorize access to drug cards for people who receive in-home professional services.

CCACs provide referrals to other community support services, including caregiver support, volunteer hospice services, transportation, adult day programs, interdisciplinary education, and pain and symptom management. Support groups, quality of life enhancement activities and bereavement programs are provided at non-residential hospices in many communities. They typically provide in-home visiting and respite by trained volunteers, but not health care professional services.

Through Ontario's health human resource strategy, the government is funding new nursing programs, including the addition of 70 palliative nurse practitioners (NP). The palliative care NP program involves 24/7 coverage for palliative clients, with the NP providing:

- Support for the Most Responsible Physician (MRP) to ensure continuity of care for

individuals with complex palliative needs across all care settings

- Consultation and mentorship
- Partnership and care connections with primary care, specialized palliative care, acute care and community care

Local Health Integration Networks (LHINs) have created plans to integrate community-based palliative NPs into their broader plans to develop regional palliative care programs.

As part of a provincial review of palliative care undertaken in 2011, the Ontario Ministry of Health and Long-Term Care (MOHLTC) partnered with the LHINs and the Quality Hospice Palliative Care Coalition to launch a stakeholder engagement strategy to identify common priorities and actions to advance palliative care delivery in Ontario. The process achieved consensus among over 80 leaders from across the health care continuum and resulted in the *Declaration of Partnership and Commitment to Action*. The Declaration outlines a vision and goals for the system, key measures of success to guide system transformation, and action plans to achieve objectives in palliative care delivery.

Through the Declaration, the MOHLTC has adopted the Canadian Hospice Palliative Care Association definition for palliative care, broadening palliative care to encompass patients in the last six to twelve months of life (the definition of palliative care in Ontario used to be "patients in the last six months of life" and varied among sectors in terms of client management and data coding) and a more inclusive of a range of chronic conditions. The Declaration defines hospice palliative care as "appropriate for any individual and/or family living with, or at risk of

developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.” Partners have committed to taking action to advance the Declaration’s recommendations, with LHINs leading the implementation efforts.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

Currently, there are no formal measures of quality indicators at the system level for the delivery of palliative care. Health Quality Ontario (HQO) is tracking indicators for quality and safety in home care, long-term care and hospitals, but these indicators are not specific to palliative care. However, some indicators for these sectors are relevant to palliative care including: incontinence, activities of daily living (ADL), cognitive function, pain, pressure ulcers, and medication safety. The long-term goal of HQO is to monitor and report on indicators for the delivery of palliative care. HQO is assessing the inclusion of standalone palliative care outcome measures that would include cognitive function, mood and depression, ADL, changes in health, end stage disease and signs and symptoms scale (CHESS), and pain. The Ministry collects high-level aggregate data from health system providers including: length of stay, diagnosis, age and gender.

At the service delivery level, no setting has formal quality indicators for the delivery of palliative care. Currently, there is no central database or registry to track all palliative patients across all sectors in Ontario. Patient information is often housed in the organization in which patients receive care. Once a patient has had a palliative care assessment, the delivery organization will record the information of the patient. Each organization has their own database including Cancer Care Ontario (CCO) and OACCAC. For CCACs, the Client Health Related Information System (CHRIS) database collects information from the Inter-RAI PC and HC, but not from the ESAS and PPS. Some CCACs are inputting information into the CCO information system and also have the capability of linking to hospital systems.

There are a variety of initiatives underway in Ontario to establish indicators for quality in home care and palliative care. The Integrated Client Care Project (ICCP) is an initiative that focuses on the integration of home care for different populations with other sectors. The project is completing an impact assessment, which will model the impact of implementing new community-based funding, costing and integrated delivery approaches in relation to four specific populations (wound care, palliative care, frail seniors and complex children). The ICCP palliative sites are delivering and testing team-based palliative care models that aim to improve the client and caregiver experience, provide support through the stages of illness preceding death and afterwards, expand access to care, and improve pain and symptom management. Integrated home care and system-wide collaboration (inter-professional teams, consultation and outreach models, etc.) are being tested through three types of site arrangements:

- *Spotlight Sites* championed by LHINs and CCACs focused on system-wide integration of palliative services, involving CCACs, home care providers, End-of-Life Care Networks, hospitals, Community Support Service agencies, residential hospices, primary care, long-term care homes and other palliative providers in the community.
- *Home Care Improvement Sites* a collaborative among CCACs and home care agencies focused on integration within home care, including integrated clinical service delivery, reimbursement and outcomes monitoring.
- *Leading Practice Assessment Site* for LHINs and CCACs that are leaders and innovators in any aspect of integrated delivery of palliative care and are willing to be evaluated.

The ICCP-PC is an opportunity for LHINs and relevant associations and health service providers to learn from the testing of evidence-based approaches to delivering care through realignment of existing resources. The performance domains and indicators for this initiative include:

- *Population outcomes* (quality of life preceding death/quality of death)
- *Cost-avoidance* (change in client utilization of resources - including use of acute care services in the last month of life (e.g., the proportion of patients having an in-hospital death contrary to their most recent expressed wishes, an ICU admission, emergency department visits and/or hospital admission prior to death; days spent in hospital); impact of unscheduled ED visits; ALC days; drug costs; 30-day re-admission).
- *Cost-effectiveness/health system impact* (change in home care costs over a cycle of care (e.g., services, supply costs, CCAC administrative and case management costs))
- *Client/family experience* (patient experience with shared decision-making, communication, symptom management, spiritual support, skill of care team, access to 24/7) (Integrated Client Care Project 2011).

The “Outcome Based Pathways (OBP)” initiative is focusing on providing guidance on indicators and instruments for monitoring patient outcomes over time to support health care providers.

Outcome pathways are being developed for: wound care, stroke care, unilateral hip and knee replacement, and palliative care (based on the Collaborative Care Framework from CCO). The quality indicators are mainly based on process rather than clinical outcomes and include the following: location of death, whether patients are dying in their preferred location, does pain management improve quality of life, are patients linked appropriately to primary care to prevent hospitalization, is there advanced care planning, and patient satisfaction and experience. Outcome based pathways for palliative care will be tested in five LHINs with focus on early identification, transition and end-of-life. The content of the pathways will be tested based on evidence and consultations with external and internal experts.

Through the *Declaration of Partnership and Commitment to Action*, Ontario is developing a report card for system, team and outcome

performance measures through service agreements in all settings (e.g., CCACs with LHINs). The Declaration indicates “a shift towards a new delivery model should be designed to achieve a balanced set of outcomes: improved quality (individual, family and provider experience); improved population health (improved quality of life); and, improved system performance/sustainability.” Four palliative measures are proposed for initial development and tracking in care settings:

1. Change (decrease) in caregiver burden;
2. Change in location of Ontario deaths (at home) relative to benchmarked performance (baseline or comparator across organizations or jurisdictions);
3. Change (increase) in quality of life preceding death/quality of death
4. Change (reduction) in avoidable hospitalizations (or change (reduction) in the rate of admissions for ambulatory care sensitive conditions (ACSCs) for palliative patients or change (reduction) in the rate of 30-day hospital readmission for palliative patients)

(See the Declaration for proposed indicators of process, quality, population outcomes and health system impact: ([http://s245089275.onlinehome.us/images/Advancing\\_High\\_Quality\\_High\\_Value\\_Report.e5e4e0cc.pdf](http://s245089275.onlinehome.us/images/Advancing_High_Quality_High_Value_Report.e5e4e0cc.pdf)).

LHINs have developed implementation plans and agreed to:

- Track a common measure of system impact: to increase the number of Ontarians who receive palliative care outside of acute care by 5-10% by the fourth quarter of 2014/15
- Select complementary indicators, for example:
  - percentage increase in key access indicators
  - number and percentage increase in patient encounters with palliative care nurse practitioners
  - number and percentage increase in OHIP claims by physicians providing home-based palliative care

- percentage reduction in overall palliative-related ALC days and inpatient days per capita among patients who died in hospital
- percentage reduction in palliative-related avoidable hospitalizations (e.g., repeat ED visits and readmissions)

LHINs have also agreed to work collaboratively with Cancer Care Ontario (CCO) to establish a Data and Performance Working Group to identify a core set of indicators to measure performance and establish a centralized process for data collection, housing and management.

In home care settings, the RAI-PC assessment tool has been implemented in 12 of 14 CCACs. The remaining CCACs are planning to implement the tool. The hospice component of the RAI-PC assessment (shorter version) is being used by

some CCACs (Toronto Central). The RAI-PC is a comprehensive assessment that is generally used once to inform the development of an individual's care plan whereas the Outcome Based Pathways provide a framework to monitor individual care plans over time. Some CCAC staff have indicated that the RAI-PC provides limited value because it is not appropriate for monitoring patients over time. The shorter version of the instrument is used more frequently. CCAC coordinators are sensitive to the assessment burden on families (especially in later stages). CCACs collect data on patient acuity through the ESAS and PPS to assess whether patients need more services (e.g., social worker). All CCACs are administering the Client and Caregiver Experience Evaluation (CCEE) to assess patient experience, an instrument used for all home care patients.

## 4.8 QUEBEC: QUALITY INITIATIVES IN PALLIATIVE CARE

### BACKGROUND

In Quebec, palliative care is managed and delivered at the regional level. Local CSSSs within regions are responsible for services at hospitals, CLSCs and long-term care, including their palliative care services. Services can vary among CSSSs. CLSCs are responsible for the delivery of home care within their jurisdiction. Many urban CLSCs have specialized palliative care home care teams that differ from other home care providers. In rural areas, palliative care is provided by the general home care program. In Montreal, there are an additional two public-private organizations that also provide home care. The areas of Verdun (Montreal) and Arthabaska (Victoriaville) are identified as regions that excel in providing palliative care in the home. Palliative services are all provided in palliative care units in hospital, hospices and in long-term care.

Patients are identified as palliative based on the use of a set of clinical indicators. A Policy for Palliative Care and End of Life was developed by the province in 2004 which included the context, principles, objectives and responsibilities under the policy. Other documents lay out core competencies of palliative care professionals

(2008), indicators for adult (2006) and paediatric (2008) palliative care, advanced care directives (2012), and end-of life and dying with dignity (2012).

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

There is not a provincial registry for palliative care. However, acute care databases can identify palliative patients based on whether they are in an acute care unit or have been seen by a palliative care specialist. Information on the diagnosis, consultations and types of services received is captured. There is a provincial database for home care and the jurisdictions are required to provide data on the volume of patients and number of palliative care interventions. Long-term care databases allow tracking of those patients documented as palliative.

The PPS or Karnofsky tools are used by some palliative care providers to measure life expectancy. The ESAS is also used, but less frequently, and often in conjunction with the Distress Thermometer. Some services administer their own patient and family satisfaction tools.

The indicators developed for adult palliative care

in 2006 fall under the following categories: place of death, resources, emergency at the end of life (e.g., contact with emergency department in the last two weeks of life), interventions (e.g., ICU, OR, resuscitation), hospitalizations, and percentage who died in hospital who had access

to palliative care services. Collection of these indicators is not widespread. However, there have been one-off provincial data collection initiatives related to palliative care.

### 4.9 NEW BRUNSWICK: QUALITY INITIATIVES IN PALLIATIVE CARE

#### BACKGROUND

In New Brunswick, RHAs are responsible for the delivery of palliative care in hospitals and health centres and for services provided by the New Brunswick Extra-Mural Program (EMP) which provides community-based services. Palliative care has been provided through the EMP as part of home health care for over 30 years. Home care is based on a generalist model with various professionals having palliative care training. Palliative care is provided in hospital palliative care units, designated palliative care beds, as well as in other hospital beds, privately-owned special care homes, long-term care, and nursing home settings. There is variation in how this care is delivered across regions (New Brunswick Hospice Palliative Care Association 2010).

Services provided in privately-owned licensed special care homes, community residences, nursing homes and long term care are legislated under the governance of Social Development. A number of agencies and non-profit organizations also provide palliative care services; there is currently one residential hospice and a number of community hospice programs.

There is not a framework for palliative care, but a palliative care advisory committee has been in place since 2012 and aims to complete the development of a strategy in 2013/14. In home care, the interdisciplinary team provide palliative care as defined by the New Brunswick EMP Palliative Care Guidelines which include standardized clinical professional assessments. Based on a provincial act, nursing home residents are required to have a care plan developed at admission, every three months and yearly. The WHO definition of Palliative Care has been

adopted (New Brunswick Hospice Palliative Care Association, 2010).

#### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

There is no formal tracking of palliative care measures. In hospital, patients are identified using CMG and ICD10 codes. The discharge abstract also provides cause and place of death. In EMP, clients receiving palliative care are coded using the 2011 CIHI MIS standard definitions. In home care, the ESAS, Edmonton Function Assessment Tool (EFAT), and PPS are used. Data entry is manual. Regions also administer patient satisfaction surveys to home care patients. The New Brunswick Health Council Home Care Survey of client experience includes clients of EMP receiving palliative care. Outside home care, these tools are used at some services, but not at others. Nursing homes use a variety of tools and this can vary by home (e.g., BRIG, mini mental, falls and skin assessments). The government is in the process of assessing the continuing care reporting system RAI-MDS in these settings. Some organizations collect data on the number of palliative patients.

Within the New Brunswick Cancer Network, work on collecting and reporting palliative care indicators is underway, including: the place of death; percentage of patients with cancer admitted to and dying in intensive care; and the percentage of patients admitted to acute care hospitals for palliative care. The first provincial cancer system report is projected to be released in 2013/14.

## 4.10 NOVA SCOTIA: QUALITY INITIATIVES IN PALLIATIVE CARE

### BACKGROUND

Nova Scotia has nine District Health Authorities and the IWK Health Centre. Specialty palliative care is delivered through these organizations. Services are determined at the district level and the range of services offered may vary. Each district has a palliative care program and they generally have specialty palliative care teams. Each of these teams has a palliative care consult nurse or clinical nurse specialist, and the team has access to a palliative care physician (who is often part time). The makeup of the remainder of the team is variable, with some having social workers, pharmacists and pastoral care. The palliative care teams may provide direct care in hospital and palliative care units or support other providers in the community, such as home care. In some districts, the team is available after hours for symptom management; in others it is not. A patient is referred to the program by a cancer centre, specialist or primary care provider (family physician or nurse practitioner). Individuals referred to district palliative care programs have historically had a cancer diagnosis. However, chronic disease and multi-morbidity in the population is increasingly an area of focus. The criteria for referral to the palliative care program can vary. In some instances, patients deemed to be at end-of-life are referred to the program; in others, it is for patients who would benefit from a palliative care approach.

The provincial home care program also provides palliative care services. There are no dedicated palliative care providers and palliative care is part of the overall caseload. There are palliative care units in five of the nine district health authorities. There are no formal palliative care or designated palliative care beds in long-term care facilities, but some larger facilities use a palliative approach to care. There are 14 hospice associations in the province which provide volunteer support services in community and hospital. However, there are no residential hospices.

There is not a palliative care framework in place

in Nova Scotia, but there has been work towards this over the last few years. Palliative care is defined as being “for individuals and families who are living with a life-threatening illness, usually at an advanced stage. It focuses on physical, psychological, social, cultural, emotional and spiritual needs of the ill person and his or her family” (Government of Nova Scotia 2013).

Work to increase awareness of advanced care planning and promote palliative approaches to end-of-life care is ongoing. A revision to a publication entitled “Preparing for an Expected Death at Home” has been recently completed to support health-care providers, patients and families in considering options for end-of-life care.

The Palliative Care Home Drug Program was introduced in 2012 and includes funding for medications. The formulary covers drugs by broad categories with no conditions or restrictions and is updated monthly to ensure new drugs are covered. To qualify for the Palliative Care Home Drug Program the patient must be assessed by a palliative care team.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

The work of the Palliative Care Access and Utilization Working Group and consultations during the implementation phase of the Palliative Care Home Drug Program provided an opportunity to review the service access and delivery and propose improvements to palliative care in Nova Scotia. This includes attention to activities related to information systems and sharing assessment and patient records among palliative care teams and community-based providers. There has been limited implementation in this regard across the province, but there is an intention to broaden the shared approach.

Nova Scotia uses the RAI tools for home care and long-term care. The Continuing Care Branch collects a number of palliative care indicators in its Seascope electronic case management system, including CIHI standardized indicators (the CIHI

Client Groupings -“End of Life” group), the RAI-HC assessment tool and the care planning process. A palliative care designation may be triggered for clients through the RAI-tools. The clinical assessment protocol (CAP) within the tool is used to guide care coordinators in care planning. The care plan itself also identifies clients as “palliative.” The implementation of the

RAI-PC assessment tool is under study.

Hospital-based palliative care programs collect a variety of data through the MIS (e.g., the number of face-to-face and telephone consults) and Discharge Administration Data (DAD). The individual’s location of death is collected through Vital Statistics Nova Scotia.

### 4.11 PRINCE EDWARD ISLAND: QUALITY INITIATIVES IN PALLIATIVE CARE

#### BACKGROUND

In Prince Edward Island (PEI), palliative care is a provincial service and is delivered primarily through home care and long-term care. There is an integrated palliative care program under the Home Care Program. The program is integrated with other sectors, including the two large hospitals (Prince County Hospital Summerside and Queen Elizabeth Hospital Charlottetown), long-term care facilities and primary care physicians. Home care staff (case managers, nurses) work with staff in these sectors and assist with advanced care planning, discharge planning, pain and symptom management and end-of-life. Patients can be referred to the program through family members, physicians and hospitals. The palliative care program aims to remain in contact with primary care physicians and encourages them to stay in touch with their patients. Currently, the program is running a pilot in a hospital in which nurses follow the patients within the integrated program and provide pain and symptom management and follow-up care.

The province has developed a Draft Strategic Framework for Palliative/End-of-life Care. The strategy outlines the key elements for each sector. For specialized support and consultation, key elements include: crisis response, specialist consultation and patient/family support. For home-based care, key elements include: advanced care planning, pain and symptom management, psychosocial, spiritual and bereavement support, personal care and respite, caregiver support, accessing financial support and long-term and community care (Health PEI 2012).

In the framework, palliative care is defined as “the specialized care of people who are affected by a serious, incurable or terminal illness, and is aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term palliative care is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure” (Health PEI 2012). Hospice Palliative Care is defined as “a philosophy of care that stresses the relief of suffering and improvement of the quality of living and dying. It helps patients and families to: address physical, psychological, social, spiritual and practical issues and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; and cope with loss and grief during illness and bereavement” (Health PEI 2012). Generally, there is no standardized definition of palliative care across all settings. Palliative care used to be defined as patients expected to live for six months. The province is moving away from this definition.

#### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

The Government of PEI does not have a central repository for the collection of information on all palliative care patients. There are two information systems – (acute and community hospital, and home care) – which are not integrated. The lack of system integration is identified as a challenge. Providers often capture information manually and information may not be available at the point of care. In the acute care sector, there are order sets for palliative care admission (anyone with a life threatening diagnosis) and last day orders (closer to dying).

The Government currently captures high-level information such as: the number of patients; place of death; average days at home; and average number days in the integrated palliative program, hospital or palliative care unit. Advanced care planning is taking place, but is not captured in databases.

The Integrated Palliative Care Program tracks diagnoses (e.g., end stage diseases, cancer). The program also administers patient and family satisfaction surveys. Recent results indicated that patients were more satisfied with care delivered outside the acute care setting. Some patients expressed dissatisfaction with the continuity of care, staff attitude, lack of communication, pain and symptom management, and administration of medication.

In home care settings, the ISM system collects the following data: age, gender, visits, phone

consultations, PPS results, and ESAS results. The PPS and ESAS tools are used at the service delivery level. ESAS is completed for a patient each visit/week. The PPS is used to calculate how many nursing hours is needed and is updated every month. A PPS score of 30 indicates the need for more home care services and a score of 40 indicates the patient needs a drug kit. These results are available to the provincial government.

In nursing homes, a modified version of the Liverpool instrument is being used. It assesses whether a: patient is moaning, groaning, frowning, agitated or distressed. It allows nurses to discuss with families whether treatment should be provided, what to treat and how to respond to someone who is dying.

## 4.12 NEWFOUNDLAND AND LABRADOR: QUALITY INITIATIVES IN PALLIATIVE CARE

### BACKGROUND

In Newfoundland and Labrador, palliative care is delivered by RHAs. Patients receive palliative care in hospitals and the community (home care and long-term care). Prior to the 2004 Health Accord, the province provided funding for medication and equipment based on the financial and clinical eligibility of the patient. With the funding from the Health Accord, the province now funds all medications and supplies related to terminal illness for patients in the last 28 days of life (end-of-life care).

The RHAs have implemented integrated palliative care teams, which are at various levels of development. These teams include physicians, community and acute care nurses. The Eastern Health Region has a palliative care leadership team supported by community, long-term care, and acute care palliative teams. An end-of-life team based in the home and community care program includes a manager, nurses, social workers, and other allied workers as well as a physician consultant. In urban areas, the team is

community-based; in rural areas teams are integrated with community, long-term care and acute care services.

There is no common definition for palliative care across all sectors. From the community perspective, palliative care is not clearly defined, but end-of-life is defined as death anticipated within one month. Two performance scales are used to assess this eligibility. Individuals who met the eligibility requirements for the end-of-life program qualify for additional medication, equipment, supplies and home support. The eligibility policy is as follows: 1) the client and family are aware of the end stage diagnosis; 2) the client requires end-of-life home care and expresses a wish to remain at home or to die at home; 3) all treatment aimed at cure has been completed and death is anticipated; 4) informal caregivers/family are able and willing to participate with the client's care plan and are available to take the major responsibility of care; and 5) a physician is available to provide support to the client.

There is not a provincial framework or strategy for palliative care, although strategies are under discussion in some regions. Accreditation Canada standards guide palliative care delivery. The Government of Newfoundland and Labrador has a strategy for cancer (Refer Department of Health website: “Gaining Ground: A Provincial Cancer Control Policy Framework for Newfoundland and Labrador”, 2010). This strategy focuses on acute care and integrated care teams. There is also “Close to home – Strategy for Home and Support Services” which focuses on strengthening palliative services in the community.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

The province has not established system or service delivery level quality indicators for palliative care and does not have a central repository for information on palliative care patients across settings. Each RHA uses the Meditech system in long-term care facilities and hospitals. There are different versions being used in different settings so data are not integrated. Instead, there is an electronic “homegrown” documentation system in which data collection is limited. This system faces challenges with accessing information since it is free-text. The data collected are mainly clinical (e.g., medications). Work is underway to merge systems.

Currently, RHAs collect information on: patient demographics, the number of patients in the program, the number discharged, the length of time in the program, the case load in the program greater and less than 28 days, the number of patients who received pain management at a facility, the number of patients who died at home who planned to die at home, and the number of patients who died in a facility who planned to die at home. There is no information collected on advance care plans or advance directives.

In home care settings, information is collected for patients at the end-of-life who receive enhanced services (e.g., age, gender, household composition, service activity, telephone visits, length of stay, discharge information). Some providers are using the PPS and ESAS tools, but they are not used consistently. The PPI is used for those with a cancer diagnosis. The RAI-HC tool is being piloted in the Western Health Authority and will likely be used in the home care sector across the other regions later this year. Currently, about 70% of long-term care facilities are using the RAI-MDS. There have been discussions regarding the use of the RAI-PC tool, a client satisfaction tool and the BRAT (which has been piloted in the Eastern Region by a bereavement counsellor). Some regions also have their own assessment tools.

## 4.13 YUKON: QUALITY INITIATIVES IN PALLIATIVE CARE

### BACKGROUND

In Yukon, palliative care services are delivered in hospitals, primary care practices, long-term care facilities and the home. The Yukon Palliative Care Program focuses on increasing capacity through consultation, education of medical professionals, families and community partners, and raising public knowledge of advanced care directives. Through the program, many communities have access to home care services, which include multidisciplinary care, grief counselling, cancer navigation at the hospital, non-government organizations (such as Hospice Yukon Society), and a primary care specialist physician. In

communities outside Whitehorse, most services are provided by advanced practice nurses who work with home care nurses. Patients also receive services in Alberta and British Columbia.

The province has adopted the CHPCA definition of palliative care, which is the last six months or year of life. However, there is no standard definition used across sectors. The insured health program has a formulary for palliative care. Physicians often determine the definition for purposes of eligibility. Currently, there is no strategy or framework for palliative care. The territory has adopted the CHPCA standards and Square of Care Model. There has been

investigation and a few trials of the Liverpool pathway, particularly in the long-term care facilities.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

Currently, there are no formal quality indicators for the delivery of palliative care at the system or service delivery level. There is no central repository for information on palliative patients. Information from the home care, long-term care and palliative care programs is not integrated with information gathered in the acute care setting. Within home care, aggregate data are collected (e.g., diagnosis, prevalence of diagnosis, number of patients with COPD, cancer, etc.) for program planning.

Currently, the RAI-HC tool is used in the home care sector and the RAI-MDS is used in the long-term care sector. There are palliative flags within RAI tools which help with identification of palliative patients (e.g., projected life expectancy less than six months; a CHESS scale greater than 3 predicts mortality). The RAI tool also collects data on pain, wound care, incontinence, and caregiver burden and support needs. In all settings, end-of-life patients are provided with an advanced care planning package. Both RAI tools

have a data item that includes whether advanced care directives are in place or not, but does not include details of this. This information is not collected in databases. The ESAS and PPS tools are used in the hospital and community, as well as long term care settings.

The RAI-PC and FAMCARE tools are not used because they are considered to be cumbersome and require further validation. There has been difficulty in determining when and how to administer the FAMCARE since it is dispensed during a sensitive time for families.

The Discharge Abstract Database (DAD) is used in the acute care sector to collect data on palliative population groups (primary, secondary, tertiary), palliative care code, physician billing, palliative surgery, location of care, and disease type. However, at times, patients are not identified as palliative.

Yukon and British Columbia were involved in the CPAC project, which allowed for the pulling of data from the RAI tools in long-term care facilities and home care, the DAD in hospitals and physician billing data. The project assisted with identifying gaps in information

## 4.14 NORTHWEST TERRITORIES (NWT): QUALITY INITIATIVES IN PALLIATIVE CARE

### BACKGROUND

In NWT, palliative care services are delivered in hospitals, long-term care facilities and home. Palliative care in the home and long-term care is provided as part of continuing care services. There are nine long-term care facilities within six communities. Home care is based on a generalist model with some nurses having palliative care training. In rural communities, palliative care is provided by community nurses and, in some instances, nurse practitioners. Physician support is provided by phone or during physician visits to the community.

The territory currently does not have a formal framework for palliative care, but there is

ongoing work in this area in terms of developing standardized assessment tools and reporting. The Department of Health and Social Services recently hosted a two-day Palliative Care Framework Development workshop with the aim to review leading practices; document the current state of palliative care services in NWT; identify challenges and gaps; and achieve consensus on the priorities going forward.

### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

Currently, there are no formal quality indicators for the delivery of palliative care at the system or service delivery level and there is no central repository for information on palliative patients.

Information from various services resides within the patient chart. The implementation of a territory-wide EMR may support improved access to patient data across the continuum. Tools such as the ESAS and PPS are not widely used. Deaths

are reported to Vital Statistics. However, data captured do not always accurately reflect the place of death unless the individual died in hospital.

### 4.15 NUNAVUT: QUALITY INITIATIVES IN PALLIATIVE CARE

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#### BACKGROUND

Palliative care in Nunavut is delivered in the home, hospital and continuing care facilities, although it is not consistent across the territory. There is not a territory-wide strategy or approach to the delivery of palliative care. Home care is delivered through the First Nations and Inuit Home and Community Care (FNIHCC) program. At this time, palliative care is not considered an essential service element of the FNIHCC program. Palliative care is often delivered through the home and community care program and services are delivered through the program where resources are available. In the communities, a palliative patient is either admitted to the home care program or flown out to Iqaluit or neighbouring provinces. The hospital in Iqaluit provides palliative care services, although there is not a designated palliative care unit. Palliative care may also be provided at the two government-run continuing care facilities (10

bed facilities) and the elders facility (8 beds), although there are no specific palliative care beds. Palliative care in the elders' centres is provided through home care.

#### PERFORMANCE MEASURES, INDICATORS, INSTRUMENTS

The home and community care program has a database which is used to collect information on program activities. Data are sent to Iqaluit for entry, including those patients receiving home care who have been classified as palliative during their assessment or who have become palliative during care. There are also data on the condition for which they are being treated, service hours, and types of care. The largest population centres have some expanded e-health.

Tools such as the RAI, PPS or ESAS are not used systematically and the hospital does not collect palliative care data.

## 5. SUMMARY

There have been significant efforts internationally in terms of developing palliative care performance frameworks and associated indicators. The Gold Standard Framework is generally the most well-known and is referenced in some instances in Canada. Few Canadian jurisdictions have a palliative care strategy or performance framework; four provinces reported having a province-wide strategy. Many international jurisdictions appear to be further ahead in this regard. These countries have explicit national priorities, goals and objectives linked directly to measures of performance. Many Canadian provinces and territories are currently talking about developing strategies and performance frameworks for palliative care and there are some activities underway in this regard. This presents opportunities for consultation and collaboration across jurisdictions for the development of provincial/territorial policies and frameworks, as well as an overarching national strategy and framework.

Nationally, the following organizations have been identified in this report as leading in the identification of best practices and measurement of performance in palliative care:<sup>1</sup>

- Canadian Institute for Health Information
- Accreditation Canada
- Canadian Hospice Palliative Care Association
- Canadian Partnership Against Cancer
- The Secretariat on Palliative and End-of-Life Care
- Provincial and national nursing associations

There are numerous validated instruments across the world that can be used for monitoring and supporting the delivery of palliative care. In the Canadian provinces and territories, there is significant variation in the extent to which data are collected and in the types of information collected. The data and indicators collected in Canada are generally not mapped to program

goals and objectives (i.e., a framework). Cancer programs tend to be further ahead in this regard. Currently, only Ontario is developing a report card for performance measures as part of the development of a palliative care strategy.

Data are generally collected either to assess patient health status or to determine resource utilization, and data collection strategies and efforts tend to be at the sector level (e.g., home care). As shown in the table below, the most common tools used in Canada are the ESAS, PPS, RAI-HC and RAI-MDS.

While the goal may be to have common tools for palliative care patients adapted to all sectors and service levels, there are **differing goals and lenses** related to measurement of palliative care services for the purposes of point-of-care delivery, quality improvement, and system performance and accountability. An important consideration is whether the measure is at the point of care, institution or program/system level. There may be a plethora measures at the institutional or point of care that support patient care, but these might not prove useful at a system and population level. Information required to inform decisions at these levels may be quite different, and how the same data are used at the various levels can differ as well.

At the system level, an important consideration is whether the focus of indicators is on quality improvement or on reporting and accountability. Stakeholders need first to determine the goals of data collection and use, and then identify which indicators best fit their objectives. For example, a focus on quality measures would likely include many process measures that may not be as useful as accountability measures. For system performance reporting, indicators are used for overall monitoring and to raise flags at the provincial level, while quality improvement efforts would focus more on the organizational level.

A palliative care framework could provide an

<sup>1</sup> Note that other national organizations may be working in this area

**Table 4.** Overview of palliative care frameworks and information collected in Canada

	BC	AB	SK	MB	ON	QC	NS	NB	PEI	NFLD	YK	NWT	NU
Common palliative care definition	X		X	X	X	X	X						
Provincial strategy/framework	X				X	X			X				
Instrument – RAI-HC	X	X	X		X		X			O	X		
Instrument – RAI-MDS (LTC)	X	X	X	O	X		X	X		X	X		
Instrument – RAI PC		O	O		X		O						
Instrument – PPS		O	O	X	O	O		O	X	O	X	O	
Instrument – PPI										O	O		
Instrument – Palliative pain assessment tool			O										
Instrument – ESAS		O		X	O	O		O	X	O	X	O	
Instrument – FAMCARE		O	O	O									
Instrument – Other patient experience			O		O	O		O		O			
Instrument – BRAT			O	O						O			
Liverpool pathway		O							O		O		

X = Wide-scale implementation, O = Pilot, sector or region specific implementation

overall structure for performance measures. A framework could define policies and objectives at the patient, service and system level and define appropriate measures at each level, with the option to align indicators at each level and develop an indicator cascade or pathway between levels.

**Strengths and weaknesses** have been identified with the ESAS, PPS, RAI-HC, and RAI-MDS. Generally, the ESAS and PPS are used to support direct patient care and the RAI tools are used to provide jurisdictions with information on resource utilization and program performance. Representatives of many Canadian jurisdictions reported that the PPS and ESAS were helpful tools and that these were preferred and useful to clinicians at the point of care. The PPS is used by many providers to assess and monitor their

patient's status, including life expectancy. The ESAS – a patient assessment of pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath – was reported to be useful in the clinical context to monitor patients, especially for change over time and assessing if there is a need for altering or adding services.

ESAS use is quite varied. It is often administered in ambulatory cancer centres and in some sectors (e.g., home care), but not others (e.g., hospitals). Some suggest that the ESAS is setting-dependent and is better administered during regular home visits weekly than daily on a hospital ward. Others report that the ESAS is helpful to flag issues at hospital admission, (e.g., high scores in particular areas show where immediate actions are required). Some stakeholders have observed

patient fatigue in regularly completing the tool and some struggle to get patients to complete it.

While these PPS and ESAS tools provide guidance at the point of care and most stakeholders report that these are most useful clinically, a few organizations and jurisdictions also use these data to look at services from a system perspective. In some instances, the indicators they use simply measure whether or not the tools have been administered to the patient and whether the results have been reviewed and/or discussed. In a few instances, aggregated data are (or can be) used to assess symptoms at a population level (e.g., the percentage high pain or dyspnea scores and the extent to which these change over time).

ESAS and PPS support symptom management (but some report not as well at end of life). However, they do not tell the whole story of the patient experience. For example, an analogue scale (e.g., 1-10 pain scale) may not effectively measure pain, may not be comparable across patients, and does not necessarily show the effectiveness of care or the care experience.

Several Canadian stakeholders identified the value of the regular administration of the RAI tools in order to look at performance at the system level over time and across jurisdictions. RAI tools are considered useful as the data are generally consistent and valid. Some suggested that RAI tools were of most value for determining resource use and program management (as opposed to patient care) and for linking a view of frontline services to program planning and administration. For example, aggregate scores at a population level have been used to evaluate and plan in home care programs (e.g., number of patients nearing end-of-life based on the CHES scores). RAI data also allow an overall program review of particular clinical aspects of care, such as the pain, wound care, incontinence, and caregiver burden and support needs. As an example, the pain scale provides administrators with information on the percentage of patients who have high scores and could trigger discussion on how the program should better address this. Several stakeholders using the RAI

tools suggest these data could be used to further monitor and support program monitoring and service delivery. Some also indicate that the RAI tool is useful at the patient level. For example, certain patient scores may trigger new assessments or treatment changes. Notably, in some jurisdictions that use RAI-HC and RAI-MDS, palliative care patients may be excluded.

Regarding the RAI-PC, several jurisdictions are piloting the tool. Some indicate that the instrument is too long, does not reflect their needs, and has not been linked to overall strategic plans. They suggest that the indicators are in development stage and may need refinement.

Other indicators identified as helpful at the system level were service data related to access, wait times, occupancy, number of encounters, type of staff visits, rates of emergency department use, hospital length of stay, terminal admissions, and admissions to the ICU in last two weeks and six months of life.

Stakeholders from the various jurisdictions in Canada identified **numerous gaps** and types of data and indicators that would be beneficial to supporting improved system and patient service delivery. These are summarized in Table 5 in the following pages.

Table 5. Additional types of information desired

Access	<ul style="list-style-type: none"> <li>• Extent of program eligibility, e.g., does the program cover suicide attempts, car accidents, victims of violence, etc.</li> <li>• Percentage of eligible patients who accessed palliative care prior to death</li> <li>• Barriers to accessing services (e.g., language, 24/7 availability, equipment, resources, etc.)</li> <li>• When in the patient journey referrals to palliative care services occur</li> <li>• Extent of palliative care support received</li> <li>• Discussions held throughout patient journey</li> </ul>
Service Delivery	<ul style="list-style-type: none"> <li>• Types of clients/demographics</li> <li>• Number of admissions</li> <li>• Diagnoses</li> <li>• Service needs</li> <li>• Type of services provided</li> <li>• Type of professionals accessed</li> <li>• Number of encounters</li> <li>• Referral sources</li> <li>• Wait time to receipt of services from referral</li> <li>• Length of stay in the program</li> <li>• Number and type of prescriptions</li> <li>• Cost by type of service</li> <li>• Costs and return on investment</li> <li>• Resources and equipment required</li> <li>• Support and infrastructure used, e.g. training, educating families, type of training needed for home support workers, requirement in communities (e.g., for rural areas)</li> </ul>
Quality of care and the client experience	<ul style="list-style-type: none"> <li>• Percentage of patients with 24/7 access to providers (e.g., in person and by phone)</li> <li>• Overall pain burden and burden over time</li> <li>• Level of skill in pain management</li> <li>• Distress symptoms (e.g., Liverpool pathway checklist: moaning and groaning, frowning, agitated, distressed, etc.)</li> <li>• Symptom management</li> <li>• Psycho-social supportive care</li> <li>• Extent to which there is person-centred or whole-person care, including patients and families</li> <li>• Patient goals in place, understood and monitored, including advanced care planning (e.g., involvement in critical decisions regarding care)</li> <li>• Ongoing quality of life measured through end-of-life</li> <li>• Patient and caregiver reported outcomes</li> <li>• Caregiver support and input (e.g., discussions held on what treatments to provide, how to be around someone who is dying) (<i>cont'd next page</i>)</li> </ul>

Quality of care and the client experience (cont'd)	<ul style="list-style-type: none"> <li>• Extent to which caregivers feel supported and empowered in the role</li> <li>• Family and client experience (e.g., social and emotion impacts, FAMCARE)</li> <li>• Bereavement support available/accessed (e.g., bereavement risk assessment tool (BRAT))</li> <li>• Satisfaction with palliative care team (e.g., approachable, ask questions, informed and empowered)</li> </ul>
Primary care	<ul style="list-style-type: none"> <li>• Identify who is delivering palliative care at the primary care level (e.g., billing code for palliative care)</li> <li>• Define palliative care physician (e.g., family physician with interest in palliative care versus a palliative care family physician)</li> <li>• Percentage of palliative care provided at the primary care level</li> <li>• Home visits</li> </ul>
Continuum of care	<ul style="list-style-type: none"> <li>• Number of different providers seen</li> <li>• Patient and caregivers can identify the Most Responsible Provider</li> <li>• Patient and caregivers experiences with transitions across the continuum of care</li> <li>• Extent of information continuity</li> <li>• Extent of access to respite care</li> <li>• Acute interventions in the last weeks of life (e.g., services in last 2 weeks)</li> <li>• Percentage of deaths in place of choice (accounting for progressive changes in patient and family and length of time in place of choice prior to death)</li> <li>• Percentage of deaths in a "reasonable place" (e.g., place of residence or palliative care designated bed versus ICU or acute medical ward)</li> </ul>

An important information gap frequently identified by stakeholders is the **comprehensive measurement of the patient and caregiver experience**, including the social, emotion and physical impacts. Many report that the psychosocial considerations are often not integral aspects of palliative treatment and care. As an example of efforts in this area, a task force at the Canadian Partnership Against Cancer is working on a conceptual framework for person-centred care that includes the patients, the family, and the patient and family together, as well as measures of supporting structures, processes and outcomes in the health care system.

A major limitation to gathering system level aggregate data is that rarely are data available at the provincial or territorial level. Few jurisdictions have **central data repositories** to support system-level performance monitoring and a

number of challenges were discussed in the context of collecting, storing and using information related to palliative care in Canada, including lag times, data accuracy and limited infrastructure. Many cannot identify at the system level which patients are receiving palliative care. Key challenges are the differing types of information collected, inconsistent definitions across siloed services, and lack of consensus on common indicators. Some stakeholders suggested that some data collection instruments are lengthy and complex and that many institutions do not have capacity to gather the data. As well, if not gathered routinely, data are less useful. Another limitation is the lack EMRs and interoperable electronic record systems that would enable central data collection. Many jurisdictions identified the need to develop a registry and cross reference data within the system to provide

greater information on service delivery and performance.

A next step would be to integrate provincial and territorial data. If jurisdictions could link and improve the use of data they could develop a national minimum data set with CIHI as a lead. However, there is currently not provincial consensus regarding palliative indicators. Challenges in this regard were reported as “indicator chaos,” a sense of overload and limited commitment. Caution was given to investing in this approach unless there was clear direction and collaboration at the provincial level.

As mentioned above, many Canadian jurisdictions are now discussing or working on developing **palliative care strategies and frameworks** and much work in this area has already been completed. Some of the key objectives identified are overcoming delivery silos, reducing duplication, ensuring patients and their caregivers get the support and care they need, enhancing the role of primary care, and improving the patient and caregiver experience across the continuum of care. A concerted effort, to share the provincial/territorial frameworks and measurement efforts would increase the body of knowledge for all stakeholders and support provincial/territorial, as well as national, efforts in this regard. The frameworks and the efforts at measurement will together advance the integration of palliative care into primary care and long-term care settings. As one starting point, The *Way Forward* initiative’s national framework provides action steps for jurisdictions and care settings to consider as they move toward better integration of palliative care for more Canadians.

In order to address some of the data challenges, a recommended approach for next steps could include:

- Creating opportunities to share provincial/territorial priorities and measurement strategies;
- Working with CIHI as the lead national agency and others interested in supporting data measurement to assist with key indicators;
- Starting with a few indicators at the program

and policy framework level, and routinely incorporating additional measures;

- Supporting stakeholders at various levels in using the data.

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## APPENDIX A: NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

DOMAIN	DEFINITION	PREFERRED PRACTICE
Structure and Process of Care	<ul style="list-style-type: none"> <li>• Comprehensive interdisciplinary assessment of patient and family</li> <li>• Addresses identified and expressed needs of patient and family</li> <li>• Interdisciplinary team is consistent with plan of care</li> <li>• Education and training</li> <li>• Emotional impact of work</li> <li>• Team has relationship with hospices</li> <li>• Physical environment meets needs of the patient and family</li> </ul>	<p>Provide palliative and hospice care by an <i>interdisciplinary team</i> of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).</p> <p>Provide access to palliative and hospice care that is responsive to the patient and family <i>24 hours a day, 7 days a week</i>.</p> <p>Provide <i>continuing education</i> to all healthcare professionals on the domains of palliative care and hospice care.</p> <p>Provide <i>adequate training and clinical support</i> to assure that professional staff are confident in their ability to provide palliative care for patients.</p> <p>Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.</p> <p>Formulate, utilize and regularly review a <i>timely care plan</i> based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.</p> <p>Ensure that on <i>transfer between healthcare settings, there is timely and thorough communication</i> of the patient's goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.</p> <p>Healthcare professionals should <i>present hospice as an option to all patients</i> and families when death within a year would not be surprising, and reintroduce the hospice option as the patient declines.</p> <p>Patients and caregivers should be asked by palliative and hospice care programs to <i>assess physicians'/healthcare professionals' ability</i> to discuss hospice as an option.</p> <p>Enable patients to make <i>informed decisions</i> about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.</p> <p>Provide <i>education and support</i> to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.</p>
Physical Aspects of Care	<ul style="list-style-type: none"> <li>• Pain, other symptoms and treatment side effects are managed using best practices</li> <li>• Team documents and communicates treatment alternatives, permitting patient/family to make informed choices</li> <li>• Family is educated and supported to provide safe/appropriate comfort measures to patient</li> </ul>	<p><i>Measure and document</i> pain, dyspnea, constipation, and other symptoms using available standardized scales.</p> <p><i>Assess and manage symptoms</i> and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family.</p>

DOMAIN	DEFINITION	PREFERRED PRACTICE
Psychological and Psychiatric Aspects of Care	<ul style="list-style-type: none"> <li>• Psychological and psychiatric issues are assessed and managed</li> <li>• Team employs pharmacologic, non-pharmacologic and complementary therapies as appropriate</li> <li>• Grief and bereavement program is available to patients and families</li> </ul>	<p><i>Measure and document</i> anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.</p> <p><i>Manage</i> anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a <i>timely, safe, and effective</i> manner to a level acceptable to the patient and family.</p> <p><i>Assess and manage psychological reactions</i> of patients and families to address emotional and functional impairment and loss, (including stress, anticipatory grief and coping), in a regular ongoing fashion.</p> <p><i>Develop and offer a grief and bereavement care plan</i> to provide services to patients and families prior to and for at least 13 months after the death of the patient.</p>
Social Aspects of Care	<ul style="list-style-type: none"> <li>• Interdisciplinary social assessment</li> <li>• Care plan developed</li> <li>• Referral to appropriate services</li> </ul>	<p>Conduct <i>regular patient and family care conferences</i> with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advanced care planning, and offer support.</p> <p><i>Develop and implement a comprehensive social care plan</i> which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decision-making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.</p>
Spiritual, Religious and Existential Aspects of Care	<ul style="list-style-type: none"> <li>• Assesses and addresses spiritual concerns</li> <li>• Recognizes and respects religious beliefs – provides religious support</li> <li>• Makes connections with community and spiritual/religious groups or individuals as desired by patient/family</li> </ul>	<p>Develop and document a plan based on <i>assessment of religious, spiritual, and existential concerns</i> using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.</p> <p>Provide information about the availability of spiritual care services and make <i>spiritual care available</i> either through organizational spiritual counseling or through the patient's own clergy relationships.</p> <p>Specialized palliative and hospice care teams should include <i>spiritual care professionals appropriately trained and certified</i> in palliative care.</p> <p>Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy, and provide education and counseling related to end-of-life care.</p>
Cultural Aspects of Care	<ul style="list-style-type: none"> <li>• Assesses and aims to meet the culture-specific needs of patients and families</li> <li>• Respects and accommodates range of language, dietary, habitual and ritual practices of patients and families</li> <li>• Team has access to/uses translation resources</li> <li>• Recruitment and hiring practices reflect cultural diversity of community</li> </ul>	<p>Incorporate <i>cultural assessment</i> as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decision-making, preferences regarding disclosure of information, truth telling and decision-making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/burial rituals.</p> <p>Provide professional interpreter services and culturally sensitive materials in the <i>patient's and family's preferred language</i>.</p>

DOMAIN	DEFINITION	PREFERRED PRACTICE
Care of the Imminently Dying Patient	<ul style="list-style-type: none"> <li>• Signs and symptoms of impending death are recognized and communicated</li> <li>• As patients decline, team introduces or re-introduces hospice</li> <li>• Signs/symptoms of approaching death are developmentally-, age- and culturally-appropriate</li> </ul>	<p><i>Recognize and document</i> the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.</p> <p>The <i>family is educated</i> on a timely basis regarding signs and symptoms of imminent death in a developmentally, age-, and culturally appropriate manner.</p> <p>As part of the ongoing care planning process, routinely ascertain and <i>document patient and family wishes</i> about the care setting for site of death, and fulfill patient and family preferences when possible.</p> <p>Provide <i>adequate dosage of analgesics</i> and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and of analgesics hastening death.</p> <p><i>Treat the body post-death with respect</i> according to the cultural and religious practices of the family and in accordance with local law.</p> <p><i>Facilitate effective grieving</i> by implementing in a timely manner a bereavement care plan after the patient's death when the family remains the focus of care.</p>
Ethical and Legal Aspects of Care	<ul style="list-style-type: none"> <li>• Patient's goals, preferences and choices are respected and form basis for plan of care</li> <li>• Team is aware of and addresses complex ethical issues</li> <li>• Team is knowledgeable about relevant federal and state statutes and regulations</li> </ul>	<p><i>Document the designated surrogate/decision-maker</i> in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.</p> <p><i>Document the patient/surrogate preferences</i> for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.</p> <p><i>Convert the patient treatment goals</i> into medical orders and <i>ensure that the information is transferable and applicable</i> across care settings, including long-term care, emergency medical services, and hospitals, such as the Physician Orders for Life-Sustaining Treatments (POLST) Program.</p> <p>Make <i>advance directives and surrogacy designations</i> available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act (HIPAA) regulations, e.g., by Internet-based registries or electronic personal health records.</p> <p>Develop healthcare and <i>community collaborations to promote advance care planning</i> and completion of advance directives for all individuals, e.g., Respecting Choices, Community Conversations on Compassionate Care.</p> <p><i>Establish or have access to ethics committees</i> or ethics consultation across care settings to address ethical conflicts at the end-of-life.</p> <p>For minors with decision-making capacity, <i>document the child's views and preferences for medical care</i>, including assent for treatment, and give appropriate weight in decision-making. Make appropriate professional staff members available to both the child and the adult decision-maker for consultation and intervention when the child's wishes differ from those of the adult decision-maker.</p>

## APPENDIX B: AUSTRALIA'S NATIONAL STANDARDS

Standard 1	Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver's and family's needs and wishes are acknowledged and guide decision-making and care planning.
Standard 2	The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.
Standard 3	Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.
Standard 4	Care is coordinated to minimise the burden on patient, their caregiver/s and family.
Standard 5	The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.
Standard 6	The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.
Standard 7	The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.
Standard 8	Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.
Standard 9	Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.
Standard 10	Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.
Standard 11	The service is committed to quality improvement and research in clinical and management practices.
Standard 12	Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
Standard 13	Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies

## APPENDIX C: LIST OF CONTACTS

CONTACT	ORGANIZATION
Natalie Damiano	Canadian Institute for Health Information
Chris Niro/Heather Howley	Accreditation Canada
Rami Rahal/Larry Librach	Canadian Partnership Against Cancer
Vicki Lafferty/Rai Brown/ David MacDonald/Patricia Gillis	Department of Health & Social Services, Northwest Territories
Jennifer Colepaugh	Department of Health & Social Services, Nunavut
Liris Smith/Heather Alton	Yukon Health and Social Services
Lisa Droppo/Georgina White/David Fry	Ontario Association for Community Care Access Centres
Debra Bell/Madeleine Morgenstern	Ministry of Health & Long Term Care
Michelle Rey	Health Quality Ontario
Rebecca Anas	Cancer Care Ontario
Sara Urowitz/Jose Pereira	Cancer Care Ontario
Marg Fitch	Sunnybrook Health Sciences Centre
Ramani Kumar	Home Community and Integrated Care, British Columbia
Anne Heinemeyer/James Silvius	Alberta Health Services
Glenn Deics	Ministry of Health, Saskatchewan
Louise Cadrin/Dan Cooper/Carmen Johnson	Regina Qu'Appelle Health Region
Lorraine Decombe Dewar	Continuing Care Branch, Manitoba Health
Mike Harlos/ Lori Embleton	Winnipeg RHA Palliative Care Program
Michel L'Heureux	Maison Michel-Sarrazin, Québec
Roberte Vautier	Palliative - Support and Primary Care Unit, New Brunswick
Linda Arseneau	Nursing Home Services, New Brunswick
Paula English	Department of Health and Wellness, Nova Scotia
Karen Milley	Eastern Health, Newfoundland
Margot Suttis/Donna Mushrow	Long Term Care and Community Support Services, Health and Community Services, Newfoundland
Mireille Lecours/Cecil Villard/ Jeanne MacDougall	Home-based and Long-term Care, Health Prince Edward Island







THE WAY FORWARD INTEGRATION INITIATIVE

Annex D - Saint Vincent Hospital  
60 Cambridge St. North, Ottawa, Ontario  
K1R 7A5

email: [info@hpcintegration.ca](mailto:info@hpcintegration.ca)  
tel: 1-800-668-2785 ext. 228  
fax: 613-241-3986

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

