

# **HOSPICE PALLIATIVE END-OF-LIFE PRIMARY CARE PROVIDER EDUCATION PROJECT: PHASE 2 REPORT**

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# HPEOL PRIMARY CARE PROVIDER EDUCATION PROJECT: PHASE 2 REPORT

## Executive Summary

Access to quality end-of-life care is an acknowledged concern as Canada's shifting demographics highlight the increasing numbers of deaths as well as changes in the nature of the dying process, including increased morbidity related to cancer and other chronic diseases. Within British Columbia collaboration in the care of patients at End-of-Life has been acknowledged as a priority within the 2008 Throne Speech, the Primary Care Charter (MoHS, 2007), and the Provincial Framework for End-of-Life Care in British Columbia (MoHS, May 2006) with identified priorities and action planning in 2008 (approved March 2009 pending release).

Partnering with the Ministry of Health Services, the health authorities, and other groups including the BC Hospice Palliative Care Association (BCHPCA) Learning Centre for Palliative Care, the BC/Yukon Canadian Strategy for Cancer Control Hospice Palliative End Of Life (HPEOL) Education Working Group has provided leadership in quality end-of life care by addressing the educational needs of health care providers. This particular HPEOL Education Working Group initiative, the Hospice Palliative End-of-Life Primary Care Provider Education Project, aimed to build capacity through the education of primary care providers in the delivery of care to all patients with a life-limiting chronic disease.

The project was conducted in two phases: **Phase One** consisted of a focus group which validated the learning needs of general practitioners and Phase Two which consisted of a developing a workshop with appropriate curriculum to support interprofessional collaborative practice amongst community primary care providers. **Phase Two**, described within this report, has validated the need for collaborative education amongst all community care providers to build awareness of the need for a palliative approach and to enhance the identification, assessment, communication and care planning for this patient population.

This Phase Two report describes the necessary understandings and the specific outcomes of this successful collaborative education workshop. Specifically, the report contains:

- The background and context for this work within the BC health care system
- A focused literature review of trends in end-of-life care, primary care, and the palliative approach to end-of-life care, providing the foundation for the content and strategies used within the workshop
- The planning and delivery of the workshop within a discreet geographic community of community primary care providers
- The workshop evaluation findings from the perspectives of the participants and the planners
- An outline of the revised curriculum including the self-audit tools and pre-reading package developed as part of the workshop planning

The entire curriculum package developed and revised for the workshop is available online through the BCHPCA Learning Centre ([www.hospicebc.org](http://www.hospicebc.org)).

The experience of the project Task Group, the results of the project, and feedback from workshop participants, have culminated in a number of recommendations. These recommendations address the following areas: building system capacity, creating practice supports, and utilizing the workshop curriculum to support the implementation of a palliative approach in the care of patients with life-limiting chronic illness by primary care providers throughout British Columbia. The recommendations were developed for decision makers and educators in Primary Care, Chronic Disease Management, Home and Community Care, and Hospice Palliative Care.

### **Recommendations 1-5: Building System Capacity for a Palliative Approach**

Participants of the workshop emphasized that system changes were required in order to enable primary providers to more fully implement a palliative approach in CDM, a finding that echoed similar feedback received during the strategic planning process undertaken by the MoHS in the fall of 2008.

The palliative approach for people with life-limiting chronic disease necessitates different clinical approaches and partnerships between primary care teams (including GPs and community-based providers), specialists providing CDM, and experts in hospice palliative and EOL care to address the EOL care needs for this population. The recognition of the palliative care needs of the population with chronic illness is relatively recent, and community-based systems in particular need to consider the best way to orient services to meet these needs.

1. Ensure that the palliative approach to care for the patients with an advance illness trajectory is a joint responsibility of involved program leaders and practitioners in Primary Care, Chronic Disease Management, Home and Community Care and Hospice Palliative Care. This will mean more clearly defining existing relationships and developing new relationships around the care of these patients.
2. Explore and clarify issues related to the roles and responsibilities of all community-based providers who may collaborate with the family physician in the care of these patients. The palliative care approach requires effective communication between care providers to avoid duplication and gaps in care and a proactive and continuous (not episodic) collaborative model of care.
3. Work with the key stakeholders to clearly define the services available from specialized palliative care programs in relation to patients with life limiting chronic illness and communicate these to primary providers working with CDM patients.
4. Use the Palliative Approach in CDM Workshop as a venue to strengthen relationships and create effective interface between all sectors and providers involved in the care of patients with life limiting chronic illness.
5. Strengthen and foster effective collaboration and partnership among HPEOL educational providers and existing educational initiatives (e.g., UBC inter-professional course; Victoria Hospice intensives, and regional educational opportunities) and education offered within chronic disease and primary care initiatives.

## **Recommendations 6-8: Creating Practice Supports for a Palliative Approach**

Practice supports aimed at enhancing inter-professional, collaborative practice in the implementation of a palliative approach in CDM are required. The supports must acknowledge the integral role of the family physician as well as other primary care providers, as well as the realities of the chronic illness trajectory and the need to develop access to effective and integrated community and home-based options for care.

The GPSC has assumed responsibility for the development of the resources to support practice changes in GP offices. If collaborative care approaches are to be supported, specific practice initiatives for other providers (e.g., CD nurses, Nurse Practitioners and home and community care staff) will be needed and will need to be linked to the practice changes being developed for GPs.

6. Identify the supports that can be accessed (educational sessions, practice tools, and specialist consultation from experts in EOL care) to support the primary care providers (GPs and other community-based providers) who provide this care.
7. Develop specific practice tools to support care of this population group by various members of the interdisciplinary team. Examples include integrating components of a palliative approach within the flow sheets for care of disease-specific groups such as COPD and congestive heart failure patients.
8. Identify methods to improve sharing of client care information between providers caring for this population.

## **Recommendations 9-11: Utilizing the Workshop Curriculum**

The Palliative Approach in CDM Workshop curriculum has been revised based on the feedback received from workshop participants, the Workshop Planning Subgroup, and decision makers who attended the workshop to ensure that the curriculum can be easily used for other interdisciplinary groups throughout the province. The BCHPCA Learning Centre for Palliative Care will partner with the MoHS, health authorities, UBC and others to ensure access to the Palliative Approach to CDM Workshop for providers throughout British Columbia and Yukon. In this work, it is recommended:

9. Provide workshops throughout British Columbia using the curriculum developed through this project for interdisciplinary groups of primary care providers as a strategy to support more collaboration in the implementation of the palliative approach to patients with life-limiting chronic illness.
10. Create capacity for delivery and uptake of this curriculum by training and mentoring local champions and developing resources for ongoing support of the palliative approach to care.
11. Develop faculty and identify financial resources to support sustainable education in the palliative approach to care throughout British Columbia.

With the conclusion of this project, the CSCC BC/Yukon will have completed their planning role and will transition this work to the BCHPCA Learning Centre for Palliative Care whose role will be to work with the health authorities, the MoHS, and other stakeholder organizations. One of the first actions for the BCHPCA Learning Centre will be distributing this report and recommendations to key end-of-life policy makers and planners in the MoHS, the BCMA, the GPSC, and health authority planners and clinicians with responsibility to develop better integrated hospice palliative care EOL services across the health care continuum.

## Introduction

The purpose of the Hospice Palliative End of Life (HPEOL) Primary Care Provider Education Project is twofold: 1) to build the capacity for educating primary care providers in end-of-life (EOL) care, and 2) to support the implementation of a palliative approach in the care of patients with life-limiting chronic illness by primary care providers.

Phase 1 of the project was completed March 31, 2009 (summarized below; see **Context**). A logic model was developed to guide Phase 2 of the project (see Appendix 1), which was initiated on March 15, 2009. Phase 2 was tasked with the following major deliverables:

1. A report that summarizes:
  - Current context for EOL care in British Columbia (including primary care, hospice palliative care, and chronic disease management) and a literature review that provides the rationale for the approach taken in developing and providing a four-hour collaborative, interdisciplinary workshop.
  - Key activities including engagement activities, a self audit completed by primary care providers regarding their current practice, curriculum development and delivery of a workshop, including evaluation and outcomes.
2. To develop an interactive practice and skills-based curriculum that can be used throughout British Columbia using the Phase 1 and Phase 2 workshop experiences regarding:
  - Identification of patients who would benefit from a palliative approach.
  - Identification of key transitions and support needs in the trajectory of illness for patients and their families.
  - Communication as the key enabler—both with patients and families across the trajectory and with other multidisciplinary health care providers.

This report summarizes the key inputs, activities, and findings from Phase 2 of the project. Although this project focused specifically on the adult population, the findings may apply to other populations. The Phase 2 report and the curriculum package can serve as a resource for those contemplating similar initiatives throughout British Columbia. The curriculum package will be available on the website of the BC Hospice Palliative Care Association: [www.hospicebc.org](http://www.hospicebc.org). Recommendations for future developments are also provided.

## Background

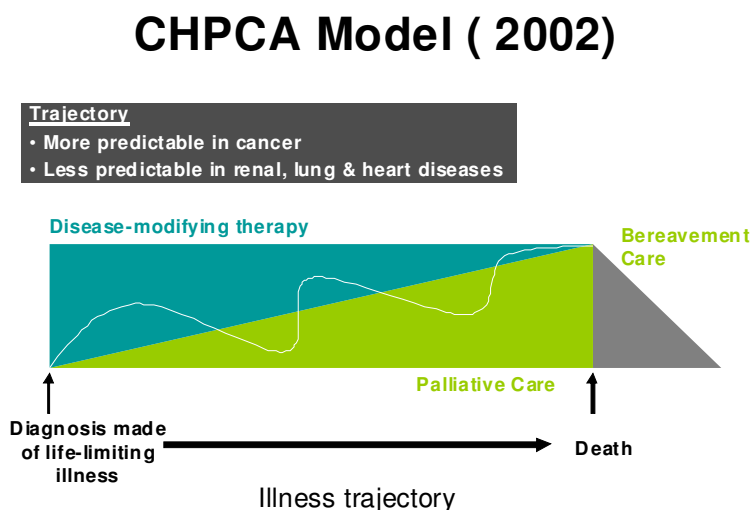
The importance and timeliness of the HPEOL Primary Care Provider Education Project is made clear by current statistics:

- More than 90% of deaths today occur as the result of end-stage and/or chronic health conditions such as cardiovascular or respiratory diseases or cancer (BC Ministry of Health Services, 2006).
- In British Columbia, currently there are just over 30,000 expected deaths a year.
- It is projected that the number of deaths per year will rise over the next 15 years by an estimated 2% to 3%, showing a 33% increase from 2004 to 2020 (Statistics Canada, 2001).
- As the population ages, there will be increased morbidity related to cancer and other chronic disease with a predicted increase in new cancer diagnoses of 70% by 2015 (Murray and Lopez, 1997).

Patients with end-stage organ failure are high users of acute care services, with most dying in hospital after aggressive treatment. These patients are often not given options for care or identified as being in need of palliative care, an approach to care that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness (Canadian Institute for Health Information, 2008). Palliative care prevents suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological, and spiritual (World Health Organization, 2003).

The care needs of patients and the supports required at end of life have been well articulated by the Canadian Hospice Palliative Care Association (CHPCA) and are seen as the concurrent therapies designed to support patients and their families living with life-threatening or life-limiting illnesses, whatever the diagnosis. Figure 1 illustrates the role of supportive care or the palliative approach to care throughout the trajectory of illness.

**Figure 1: The Role of Hospice Palliative Care During Illness (CHPCA, 2002)**



Adapted from the CHPCA Model

In British Columbia, full-service general practitioners (GPs) and other primary care providers provide the majority of care at the end of life with variable access to hospice palliative supports available through the health authorities. Most patients who are cared for within traditional palliative care programs have a cancer diagnosis with a defined trajectory. But for non-cancer patients, EOL care can be more challenging because the trajectories may be unpredictable due to either acute exacerbations of disease or a very slow decline over many years. This makes prognostication difficult, and as a result, many patients with chronic life-limiting illness may not be identified as requiring palliative or supportive care, and therefore their needs, may not be addressed.

Recognizing the current gaps and increasing demands for hospice palliative EOL care, and also recognizing that quality EOL care was identified as a priority in the 2008 Throne Speech, the provincial EOL Standing Committee of the Ministry of Health Services (MoHS) identified that provincial direction and improved standardization of EOL care was required. In 2008, the MoHS conducted a strategic planning process with the health authorities and key stakeholders to identify and recommend key priorities, strategies, and actions for the next five years, based on the Provincial Framework for End-of-Life Care in British Columbia (MoHS, 2006). The draft provincial strategy and action plan for hospice palliative EOL care in British Columbia was approved in March 2009 but has not yet been released.

The National Institutes of Health (2004) defines the end-of-life as the period marked by disability or disease that is progressively worse until death, and notes that care provided during this time is sometimes called hospice care, comfort care, supportive care, palliative care, or symptom management. Consistent with this definition and in concert with EOL strategies being developed in other countries, BC is moving toward an expanded definition of end of life, recognizing that the need for EOL care begins earlier in the illness trajectory than may have been previously identified. This earlier integration of hospice palliative care within the illness trajectory is now referred to as the palliative approach to care.

Educating primary care providers in EOL care and in the implementation of the palliative approach across the continuum of care will require education and practice supports. These supports will help GPs and other health care providers in their important role in identifying, assessing, and providing EOL care for patients with life-limiting illnesses. Also, over time, this population-based approach will help clarify and define the need for specialist services and resources (i.e., hospice and tertiary beds, mentoring and education, and other services) coordinated by the health authorities in partnership with primary care providers.

EOL care has also been identified as a priority within the Primary Care Charter and by the General Practice Services Committee (GPSC), a joint committee of the BC MoHS, the BC Medical Association (BCMA), and the Society of General Practitioners. Members of the BC Primary Care Council attend as guests and represent the health authorities of BC. Primary care initiatives are currently advancing a population-based approach for chronic disease management (CDM) patients through a number of strategies, including the following initiatives:

- Integrated health networks.
- CDM clinics and pathways.
- Divisions of Family Practice and the Practice Support Program for GPs.



These primary care and CDM initiatives have made a significant and positive impact on the health of the population. However, most do not include advice in relation to the final phase of illness or identify strategies to integrate the supportive and palliative care needs of patients approaching the end of life. There is a need to address the ways in which the palliative approach to care can be integrated into care alongside disease-modifying therapies and functional enhancements.

The GPSC end-of-life initiative, which includes a Practice Support Program and fee code changes effective June 1, 2009, was formulated with awareness of the needs of this vulnerable population and with the goal of optimizing EOL care by full-service family physicians. The BCMA Practice Support Program, with a structured practice-based approach for GPs and medical office assistants (MOAs), has been shown to be successful at changing practice outcomes for GPs in other areas of CDM. The EOL care initiative is the most recent focus of the BCMA Practice Support Program. It had its initial planning meeting in June 2009, and it will target full-service family physicians and their MOAs, with some involvement of other primary care providers to be determined. No curriculum currently exists in British Columbia for a more collaborative approach by all primary care providers (GPs and community-based providers) in the palliative approach to care.

## Context

The BC/Yukon Canadian Strategy for Cancer Control (CSCC) HPEOL Education Working Group (see Acknowledgments) was formed in 2006 to develop an education action plan for workforce development and education for HPEOL service capacity in BC and Yukon in partnership with the BC Hospice Palliative Care Association, the MoHS, and other HPEOL providers in BC and Yukon. This group has completed several major initiatives, including a blueprint for action and a preliminary background paper providing baseline data on educational gaps in present and future HPEOL care professionals. It has also helped host a workshop with an international expert in population health planning. These activities identified the need for a population health planning approach to care delivery for all patients at end of life with education as the key enabler.

In November 2008, BC/Yukon Canadian Strategy for Cancer Control HPEOL Education Working Group, in partnership with the BC Hospice Palliative Care Association's (BCHPCA's) Learning Centre for Palliative Care (a provincial group of palliative care educators working in academic and clinical settings), identified an opportunity to provide leadership and a support structure for the development and implementation of an educational initiative that would support education of primary care providers in the palliative approach to care. The goal was to identify learning needs and develop a curriculum that could be used provincially to move toward a more standardized approach to educating primary care providers, including GPs, nurse practitioners (NPs), and others.

Supported by a \$25,000 grant from the BC/Yukon CSCC, a Workshop Task Group was identified to provide leadership for this project. The leader of the Workshop Task Group is Dr Doris Barwich, Medical Director of End of Life Care in Fraser Health and Chair of the BCHPCA Learning Centre for Palliative Care and of the BC/Yukon CSCC Education Working Group. The following clinicians and educators are also members of the Task Group:

- Dr Fraser Black, Medical Director, Victoria Hospice
- Dr Neil Hilliard, Palliative Care Physician, Fraser Health Hospice Palliative Care Program and Lead for the Palliative Care Guideline Development Project, BCCA Family Practice Oncology Network
- Dr Peter Kirk, Head Division of Palliative Care, UBC Department of Family Practice
- Dr Douglas McGregor, Medical Director, Palliative Care, Vancouver Coastal Health
- Ms Pat Porterfield, Regional Leader, Palliative Care, Vancouver Coastal Health
- Dr Chris Rauscher, Clinical Advisor, Ministry of Health Services, Primary Health Care Team
- Ms Della Roberts, CNS End of Life Care Fraser Health, and Lead for the Workshop and Curriculum development
- Ms Susie Wai, Executive Director, BC/Yukon Canadian Strategy for Cancer Control

The Primary Care Provider Education Project was organized to be carried out in two phases.

**Phase 1**, completed March 31, 2009, was supported by additional funding from Vancouver Coastal Health Authority (VCHA) and led by Ms Pat Porterfield and Dr Douglas McGregor in association with the Workshop Task Group. This phase brought together a group of GPs to provide feedback on a model and competencies for the role of GPs and other primary care providers throughout the trajectory of illness. Input was obtained on their learning needs and potential tools and resources.

A GP focus group was held on March 3, 2009, with strong endorsement of much of the material presented (summarized in a report completed April 23, 2009).

The goal of the focus group was to inform **Phase 2** of this project. It will also inform the activities of the planning group for the Practice Support Program planned regarding EOL care. The feedback received from the focus group session led to a recommendation that an educational module focus on improving competencies in the following areas:

- Increasing skills in the ability to identify patients with life-limiting illness who may benefit from a palliative approach.
- Increasing comfort and competencies in communicating with patients and families and advance care planning.
- Increasing skills and competencies in providing pain and symptom management care, with a particular focus on opioids and medication management.
- Offering opportunities to promote shared care with specialists and, in particular, with the BC Cancer Agency.

With the announcement of the BCMA EOL Practice Support Program, which primarily targets GPs, just prior to the Phase 1 workshop, and given that no curriculum has been developed in British Columbia specifically for a more collaborative approach by all primary care providers (GPs, NPs, and other community-based providers) in the palliative approach to care, the purpose of Phase 2 was amended to address the needs of a broader group of interprofessional primary care providers. The intent was to improve the quality of care for CDM patients with life-limiting illness through better communication and collaboration in the identification and assessment of, and care planning for, those who could benefit from a palliative approach. This would be accomplished by developing, providing, and evaluating a four-hour collaborative, interdisciplinary workshop and the related curriculum products for these primary care providers.

It was intended that the curriculum products developed would be used by the BCHPCA Learning Centre for Palliative Care in association with the MoHS, the health authorities, and others to address the gaps in care for this population and to complement and inform the Practice Support Program for GPs and model the integrated, collaborative interprofessional teamwork that is the basis of hospice palliative care services. Further, it was recognized that hospice palliative care education is traditionally not delivered using the approach taken in the GPSC Practice Support Program, and that developing and delivering this workshop would enable a better understanding by hospice palliative care providers of the education and practice supports necessary to support primary care providers in the care of their patients with life-limiting chronic disease. This understanding was key to creating an effective curriculum that could be implemented throughout British Columbia. It was anticipated that the initiative would also lead to recommendations for future initiatives in this area.

# Key Inputs and Activities

## ***Literature Review: Rationale for Workshop***

Given the project constraints, a focused literature review was conducted to provide the rationale for the project and the approaches taken in the workshop. It focused primarily on the new reality of palliative EOL care and the provision of palliative EOL care by generalists, rather than specialists in palliative care. The literature review also established the rationale for key workshop themes.

## **NEW REALITY OF PALLIATIVE CARE/END-OF-LIFE CARE**

**Lynn**, an advocate of making quality services available for all seriously ill persons coming to the end of life, points out that the great success of modern medicine has been to transform acute causes of death into chronic illnesses. That is, the chronic illness may be stable or progressive but is not perceived as life threatening. Eventually, however, there are a set of conditions that are fatal and death is often perceived as sudden or unexpected (Lynn, 2005, p. S14).

Lynn proposes that reform is needed and that service delivery arrangements should be tailored to service the three common trajectories that people tend to follow in their last phase of life. She proposes that care for patients in these trajectories should focus on care arrangements that stay with the patient and family across time and settings and that are comprehensive across care needs. She suggests that there are three common trajectories of dying:

1. Long maintenance of good function with a few weeks or months of rapid decline. Cancer is the most common diagnosis. These patients need supportive hospice care for themselves and their family during the period of rapid decline. About 20% of people follow this course.
2. Slow decline in physical capacities interrupted with serious exacerbations and with death often coming rapidly. A variety of diseases follow this course, chronic heart failure and emphysema being the most common. These patients benefit from preventing exacerbations and by being provided with early treatment (often in the home) and support for decision making with good advance care planning. About 25% of people follow this course.
3. Long-term dwindling of function needing years of personal care (mostly frailty and dementia). These patients need long-term care services at home or in residential care, and support for family caregivers is also needed. About 40% of people follow this course.

There are some difficulties, however, in addressing EOL care needs for the broader group of patients as most care providers still look for indicators that someone is actively dying or clearly in the last months of life before palliative or supportive care is offered. In addressing this issue, a panel at the National Institutes of Health (NIH) State of the Science Conference on Improving End-of-Life Care drafted a statement based on the scientific evidence presented in open forum and in the published scientific literature. The statement noted the following:

- Evidence does not support a precise definition of the interval referred to as “end of life.”
- End of life is usually defined and limited by the regulatory environment and criteria for specific resources, rather than by scientific data.
- End of life should not be defined by a specific timeframe unless evidence can support reliable prognostication.

- Regulatory definitions are often a barrier to improving care and research related to end of life.

Pointing out the lack of definitional clarity, the panel noted that the evidence supports two components for end of life: 1) the presence of chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate, and 2) the symptoms or impairments resulting from the underlying irreversible disease require care and can lead to death (NIH, 2004).

**Bern-Klug** promotes a broader conceptualization of the end of life to include not just the time when death is clearly foreseeable but also the time when someone is at a greatly increased risk of death, although the exact timing is unclear (Bern-Klug, 2004). Bern-Klug uses the term “ambiguous dying syndrome” to refer to people in this situation and argues that the current narrow definition of dying determined by a clear prognosis related to time of death can “rob dying individuals and families of the opportunity to fully participate in decisions related to medical treatment, use of financial and community resources, as well as the use of remaining physical and emotional energy” (Bern-Klug, 2004, p. 56).

Traditional specialized palliative care services have focused care within existing resources on the group with cancer where the prognosis is most reliable. For example, many specialized palliative care services require a prognosis of less than six months for admission, as this period was known to be the timeframe in which the person experienced the greatest decline and thus had the greatest needs. But by defining EOL care with fixed timeframes, a significant number of individuals and families will be deprived of the comfort and assistance of the palliative approach. The palliative approach integrates many of the lessons learned in providing hospice palliative care to those in the rapidly declining trajectory and can inform the shape of EOL care for those in other trajectories. Practice guidelines such as the Canadian Hospice Palliative Care Association Norms of Practice document describing a person-centred, interdisciplinary approach to the delivery of care can provide helpful frameworks for all three trajectories.

- The **Palliative Approach to Chronic Disease Management Workshop** focuses on care for patients defined by Lynn’s second trajectory: those living with a life-limiting chronic disease. The workshop has been designed to assist primary care providers to integrate palliative care principles and approaches with CDM in the care of patients who have a life-limiting illness, although their prognosis related to time of death is unclear.

## **GENERALIST CARE**

Much EOL care is provided by generalists such as family physicians, home and community care programs and services that provide a variety of health care providers in home and home-like settings, and staff in residential care. Generalist EOL care is a major focus of health policy in the UK and Australia.

**Shipman and colleagues** report the results of a national consultation and prioritizing exercise in the UK to identify parameters and concerns in generalist EOL care (Shipman et al., 2008), defined as care provided by health or social care professionals who were not specialist palliative care providers. They noted that there was no uniformity in understanding the meaning of EOL care, with perceptions ranging from more than a year to the last few days of life. Concerns were identified during the consultation related to the challenges of prognosis (time to death) and the

availability of adequate support for patients with advanced non-malignant disease. Participants in the consultation noted that specialist palliative care services dealt largely with cancer.

A major concern identified among all groups consulted was the variability of standards of generalist EOL care. Not only were generalists usually caring for only a few patients who were in the end-of-life phase at any point in time, making it difficult to keep up skills in this area, they were also limited by a lack of educational opportunities. In addition, it was identified that more needs to be known about effective models of care and how they can be integrated into the workload of the generalist provider.

Australia has developed a population-based model that defines the health needs of people with life-limiting illness. **Palliative Care Australia** identifies three groups within this model (Palliative Care Australia, 2005, p. 14):

- Subgroup A is the largest and comprises those patients who have low complexity or intensity of palliative care needs that can be managed by their primary care providers or other specialist staff such as cardiologists. Currently almost two-thirds of all people whose death is expected fall within this group and may not need to be seen by specialist palliative care services prior to their death. The majority of these patients have a diagnosis of non-malignant disease.
- Subgroup B requires intermittent support from specialized palliative care services, with varying levels of involvement depending on the complexity of care needs including episodic consultation or shared care.
- Subgroup C includes patients with the most complex care needs who require ongoing support from specialist palliative care providers.

Several studies have examined issues related to the provision of palliative care by family physicians. **Groot and Vernooij-Dassen** carried out focus groups with GPs in the Netherlands to identify their opinions of their tasks in palliative care and the barriers encountered in performing these tasks (Groot and Vernooij-Dassen, 2005). There was agreement that the provision of palliative care was a difficult but rewarding job and included both somatic and psychosocial care. On the issue of GPs assuming responsibility for the coordination of care, there was some debate. They identified barriers in three groupings: 1) personal (e.g., competence, time); 2) relational (e.g., communication and coordination with others such as family and other providers involved in the care); and 3) organizational barriers that impede effective care (e.g., delay in access to needed care).

In Canada, **Brazil and colleagues** conducted an interprofessional workshop for 46 individuals from across Ontario that was designed to 1) share key information from three palliative care demonstration projects (funded through the Primary Health Care Transitions Fund); 2) identify key features that should be recommended for model development; and 3) achieve consensus on essential components to increase primary care capacity in palliative care. All three demonstration models included varying levels of support for primary care physicians by palliative care specialists. There was consensus on two key themes: 1) every person has the right to quality palliative care; and 2) primary care physicians are in a key position to provide such care if they are well prepared and are provided with adequate support (Brazil et al., 2007).

Key features recommended for the palliative care model included integration or support of the family physician with a palliative care team (palliative care physician, advanced practice nurses

and psychosocial counselling); standardized clinical assessment tools; and interprofessional training and practice-based education by a palliative care physician in a family practice setting. The relationship of other generalist providers such as home care nurses and case managers with the primary care physician and the specialist team was not clearly articulated in this article.

**Curtis and colleagues** describe a qualitative study designed by using focus groups to develop a comprehensive understanding of the factors contributing to the quality of physicians' care for dying persons (Curtis et al., 2001). The focus groups included patients with cancer, AIDS, and chronic obstructive pulmonary disease (COPD); family members of those who died of a chronic disease; nurses and social workers from hospice or acute care settings; and physicians with expertise in palliative care. Content analysis was used and 12 domains of physicians' skills were identified for providing end-of-life care. These 12 skills were grouped into five categories: cognitive skills, affective skills, communication skills, patient-centred values, and a patient-centred care system. All 12 domains were identified by patients in all disease groups, and the most commonly referenced domains were similar across disease groups. This article suggests that the skills in providing effective EOL care are not disease specific and thus supports the focus on generalist primary care providers.

**Stuart** proposes a change in the community-based system to better integrate and support the needs of patients at the end of life. He points out that the needs of the chronically ill are often not met by either acute hospitalization directed at those expected to recover or by hospice care directed at those expected to die. He argues that home care is well suited to manage the transition from acute to supportive care. However, to be effective home care needs to provide ongoing care and support rather than episodic care (Stuart, 2003). Although this article addresses issues inherent in the US model, the transition-based approach would be relevant to all community-based providers.

- The **Palliative Approach to Chronic Disease Management Workshop** targets generalist primary care providers. Family physicians with full-service practices care for many of these individuals. In addition, most individuals with progressive life-threatening chronic illnesses are further supported by services received through Home Health Services. Case managers, chronic disease nurses, nurse practitioners, respiratory therapists, and rehabilitation therapists are key providers of care. Consequently, these individuals were invited to attend the workshop.

## **RATIONALE FOR THE KEY WORKSHOP THEMES**

The findings from Phase 1 and the review of the literature led to the development of the key themes to be included in the **Palliative Approach to Chronic Disease Management Workshop** (see Appendix 2—Invitation to the Workshop):

- Identification of those who could benefit from a palliative approach to care.
- Communication and advance care planning.
- Assessment and monitoring; pain and symptom management.
- Teamwork, collaboration, and appropriate referral.

### ***Identification of Those Who Could Benefit from a Palliative Approach to Care***

A key element of supporting practice-based change is to help participants identify a priority population. In her article, Lynn refers to the surprise question: Is this person sick enough that it would be no surprise for the person to die in the next six months or year? She acknowledges that some individuals identified by this question may live for years in a fragile state and some will die soon, but all typically need the services that are priorities in the last part of life including support for advance care planning (including identifying preferences and priorities for managing the terminal phase of illness), comfort measures, symptom management, assistance for daily living, and family support (Lynn, 2005). This surprise question has now been validated in several studies as a reliable indicator of EOL care needs. The surprise question has been used as the basis for various Institute of Health Care Improvement initiatives to identify a priority population that may require supportive or palliative care approaches.

A number of initiatives have been directed at assisting primary care providers in identifying those needing a palliative care approach. The Gold Standards Framework (GSF), implemented throughout the UK by the National Health Services End of Life Care Programme, is a systematic practice-based approach to optimizing the care for patients nearing the end of life provided by primary care teams in the community. The framework notes that earlier recognition leads to better planning, better communication, and better care.

The GSF Prognostic Indicator Guidance tool was developed to promote earlier recognition of people nearing the end of life. This document lists three triggers to identify patients who would likely benefit from supportive/palliative care (National Gold Standards Framework Centre, 2008). These triggers are:

- The surprise question: Would you be surprised if this patient were to die in the next six to 12 months?
- Choice/Need: The patient with advanced disease makes a choice for comfort care, or is in need of supportive/palliative care.
- Clinical indicators: Specific indicators of advanced disease for each of the three main EOL patient groups: those with cancer, those with organ failure, and those who are elderly and frail or have dementia.

The Prognostic Indicator Guidance tool is not intended solely to assist in identifying those patients who are nearing the end of their lives but to *improve prediction of need for support* and thus to support more patients nearing the end of life whatever their underlying illness (keeping in mind that many programs and services have been oriented primarily to the cancer trajectory and not to patients living with and dying from other underlying illnesses). It can also prompt a health care professional to initiate discussions about patient preferences and help to improve care aligned to patient preferences and prevent crises. Implementing the framework has improved aspects of palliative care in the UK, but there are variations in the extent to which this has occurred in general practice teams (Shipman, 2009).

In Canada, the Ontario Guidelines Advisory Committee has developed a clinical practice guideline entitled Palliative Care: Recognizing Eligible Patients and Starting the Discussion. This guideline identifies a number of factors, including the surprise question, to identify these patients. It also provides guidance related to beginning a palliative care discussion with patients and assessing the patient's needs and values with respect to palliative care. A similar guideline regarding the palliative approach to care has been developed by the BC Cancer Agency Family Practice Oncology



Network for the BCMA Guidelines and Protocols Advisory Committee. This guideline is currently being circulated for final review before release to all GPs in the province.

- **Application of theme to the workshop:** The workshop includes identification of patients nearing the end of life as one of the key themes. This focus has been validated through the Phase 1 GP focus group findings.

### ***Communication and Advance Care Planning***

Communication is a key enabler of improvement in EOL care for all trajectories. **Wenger and Rosenfeld** describe the use of an expert panel to identify 14 indicators that were judged sufficiently valid for use as measures of the quality of care for vulnerable elders (Wenger and Rosenfeld, 2001). The indicators outlined are based on observational data and consensus opinion. Of the 14 indicators identified, nine relate to communication issues, including identification of preferences, patient participation in decision making, documentation of preferences, ensuring continuity of care preferences, and consistency of care with care preferences. The remaining five indicators relate to care of the dying patient (e.g., symptom management). The authors note that communication about prognosis, elicitation of preferences, and translation of preferences into care are essential to quality medical care.

Addressing communication and care planning needs is also cost effective and improves quality of care. **Zhang and colleagues** report the results of an observational study of 627 patients with advanced cancer (Zhang et al., 2009). Patients were interviewed at baseline (on average six months before death), and following death the costs of care received in the last weeks of life were aggregated. The EOL care and quality of life in the final week were reported by nurses or informal caregivers. Patients with advanced cancer who reported having end-of-life conversations with physicians had significantly lower health care costs in their final week of life and higher costs were associated with worse quality of death. However as this was only an observational study, it is not possible to conclude that there is a causal relationship between EOL conversations and cost differences in the last week of life. Nevertheless, the study underscores the importance of conversations and the link to better quality care as assessed by care providers and family and, interestingly, less cost to the health care system.

- **Application of theme to the workshop:** Effective communication underlies all processes in the provision of quality care for patients and among health care providers. Specific information regarding communication skills and skill development related to communication, identification of goals of care, and advance care planning incorporating best practices from the US and Canada are incorporated into the workshop. This second theme has also been validated by the GP focus group findings from Phase 1.

### ***Assessment and Monitoring: Pain and Symptom Management***

Once the client's care goals are clarified, care planning can focus on improving the quality of care and aligning care with patient and family preference and ensuring appropriate management of pain and other symptoms. Although assessment and management of symptoms have been most thoroughly studied in patients with cancer (National Institutes of Health, 2004), there is emerging evidence-informed guidance available to assist care providers with EOL care assessment, monitoring, and symptom management for those patients with chronic illnesses other than cancer (Hutchinson, 2005; Turriss and Rauscher, 2005).

A recent article by **Lorenz and colleagues** describes a systematic review of the evidence for improving palliative care at the end of life (Lorenz, 2008). The review included cancer, chronic heart failure, and dementia patients. They found strong evidence to support interventions to improve important aspects of EOL care including the treatment of cancer pain with various effective therapies, the use of opioids to treat dyspnea in advanced lung diseases, the use of various effective therapies to treat depression, and multidisciplinary interventions to improve continuity of care particularly in advanced heart failure. They also found moderate evidence to support advance care planning led by skilled facilitators and interventions to alleviate caregiver burden. Further, they noted that strengthening the evidence base for the care of patients with advance illness is crucial in order to assure the best quality of care throughout the lifespan; this point is critical due to the rapid aging of our population.

- **Application of theme to the workshop:** Given that the initial workshop was only four hours long, it was decided that this theme would be limited to an overview of approaches related to assessment and care planning. Specific tools to support symptom assessment and impact of the disease on the patient and family were provided. The use of opioids for dyspnea was highlighted as an example of symptom management concurrent with disease-modifying therapy. Dyspnea is a frequent symptom in advanced heart, lung, and renal disease, and there is well-established evidence for the effectiveness of opioids for dyspnea in palliative care.

### ***Teamwork, Collaboration, and Appropriate Referral***

The palliative approach incorporates an interdisciplinary team in the provision of collaborative patient-centred care. Currently, EOL care is often fragmented among providers and provider settings, leading to a lack of continuity of care and impeding the ability to provide high-quality interdisciplinary care (National Institutes of Health, 2004).

There is a current emphasis in Canada on collaborative practice, and a number of primary care transition projects have been funded in this area. Collaborative patient-centred practice is designed to promote the active participation of each discipline in patient care. It enhances patient- and family-centred goals and values, provides mechanisms for continuous communication among caregivers, optimizes staff participation in clinical decision making within and across disciplines, and fosters respect for the disciplinary contribution of all professionals (Curran, 2004, p. 1). The provision of collaborative care has been reported to be most important when patients have complex care needs (such as in EOL care) requiring more than one discipline's set of skills and knowledge. Care providers are usually educated in discipline-specific silos and need specific education in order to provide patient-centred interprofessional team practice. Small group learning methods are identified as key strategies for facilitating interprofessional education (Curran, 2004, p. 10).

The team working with the patient's primary care provider (usually a family physician) will need to be identified and the care providers supported in an interdisciplinary collaborative model of care. The skills of specialist palliative care teams may be required to meet the needs of some of these clients. Australia Palliative Care estimates that about one-third of patients need consultation or ongoing support from a specialist palliative care service. The current mandates of such specialized teams in British Columbia may need to be clarified so that appropriate referrals can be accepted even when the prognosis is not clear.

Few initiatives have focused on providing interprofessional education to a collaborative group of providers, although team-based care is a foundational element of both hospice/palliative and CDM approaches to care.

- **Application of theme to the workshop:** In recognition of the importance of interprofessional care in the provision of a palliative approach to care, the Workshop Task Group determined that the workshop would focus on an interprofessional group of generalist care providers (family physicians, case managers, chronic disease nurses, and others). Developing strategies to support collaborative practice, including small group learning methods, is also a focus of the workshop.

## ***Workshop Planning and Delivery***

Based on the literature and the key themes identified in Phase 1 of the project, the following goal for the Palliative Approach to Chronic Disease Management Workshop was established:

- To improve the quality of care for chronic disease management patients by improving communication and collaboration in the identification, assessment, communication, and care planning for chronic disease management patients who could benefit from a palliative approach to care.

The overall strategy was to develop, provide, and evaluate a four-hour interdisciplinary workshop designed to promote the implementation of a palliative approach to care by primary care providers in the management of patients with chronic, life-limiting illnesses to align with EOL initiatives of the MoHS and General Practice Services Committee (GPSC).

### **Workshop Objectives**

The following objectives were set out for the workshop:

1. Establish a baseline regarding current practice in primary care for patients with chronic life-limiting disease by various primary care providers.
2. Engage primary care providers and promote collaborative practice in the provision of a palliative approach.
3. Identify why it is important to identify patients early (improved outcomes).
4. Identify those patients in the primary care provider's practice with chronic disease who would benefit from a palliative approach in care (integrate the palliative approach to care with disease-modifying therapies and improve patient and family satisfaction and outcomes).
5. Identify patients who would be appropriate to refer for specialist palliative care consultation and service and know how to access hospice palliative care consultation.
6. Become familiar with assessment and care planning tools and resources that will support implementing a palliative approach.
7. Enable the initiation of advance care planning conversations.
8. Explore the barriers (emotional and practical) to practice to incorporate a palliative approach and the possible strategies to address these barriers.
9. Identify learning needs of interdisciplinary team members that are the same as or distinct from family physicians/GPs.
10. Teach in an interactive, practice-, and skills-based interdisciplinary style.

### **The Planning and Delivery Process**

The following steps were followed to develop and deliver the workshop. In this case, financial support for the venue and catering costs (from CSCC) and sessional funding to support physician attendance (from Fraser Health HPEOL program) had been identified prior to the workshop. Support for faculty attendance was provided by their respective organizations.

## **1. Establishing a Planning Group**

Dr Doris Barwich, Chair of the BC/Yukon CSCC Education Working Group provided overall leadership for both Phase 1 and Phase 2 of the project to ensure continuity. A project task group was established early on to provide leadership and content expertise throughout the project. For Phase 2, Ms Della Roberts assumed leadership for the curriculum development and the implementation of the workshop. Key planning support was provided by a subgroup of the Workshop Task Group. The members of this Workshop Planning Subgroup were Ms Della Roberts (lead), Dr Doris Barwich, Dr Douglas McGregor, Ms Pat Porterfield, Dr Chris Rauscher, and Dr Neil Hilliard, with input from the Workshop Task Group as needed. Although no primary care providers sat on the planning group, input was received from Dr Brenda Hefford and Ms Linnea Robinson, Home Health Case Manager in White Rock South Surrey, in planning the workshop. These conversations helped to mold the workshop content and process.

## **2. Selecting the Location**

To support the objective of fostering collaborative practice, it was decided to host the workshop in a geographic community of practice location and to invite interprofessional primary care providers from that community. The White Rock South Surrey (WRSS) community was chosen as the location for several reasons: 1) an integrated health network was being formed in WRSS with CD nurses recently hired into a number of family physician practices over the past two years; 2) the WRSS Division of Family Practice is newly formed and is a prototype for other divisions throughout British Columbia with an identified interest in EOL care; 3) in 2007/08 focused support had been provided to increase awareness and use of advance care planning throughout the WRSS community; and 4) good relationships existed between the hospice palliative care providers and the WRSS primary care providers.

## **3. Engaging Key Stakeholders**

Conversations were held with various key stakeholders within Fraser Health (FH) in preparation for the workshop by Dr Doris Barwich, Medical Director for Hospice Palliative and End of Life Care in FH, and Ms Della Roberts, Clinical Nurse Specialist who had provided hospice palliative care leadership in WRSS for several years prior to accepting the position of CNS for EOL Care initiatives in FH. Individual meetings were held and support for the workshop was sought and gained from the following people:

- Ms Colleen Hart, FH Executive Director Primary Care Initiatives
- Dr Brenda Hefford, FH Physician Executive Lead for Primary Care and Head of the Division of Family Practice White Rock South Surrey
- Ms Susan Brown, FH Executive Director for Chronic Disease Management
- Ms Carolyn Tayler, FH Director for Hospice Palliative End of Life Care
- Ms Sandra Geddes, FH Director for Home Health in White Rock South Surrey (WRSS)
- Ms Michelle Medland, FH Project Coordinator for Primary Care and Community Networks

## **4. Identifying Key Content, Developing Curriculum, and Obtaining CME Credits**

The four key themes identified from the literature and validated in Phase 1 provided the foundation for the workshop curriculum. Strategies were identified to meet each of the established

program objectives. (See Appendix 3 for a full list of strategies developed to meet each objective.) A workshop outline was then developed based on the objectives and strategies, recognizing the constraints of the timeframe of the workshop.

The workshop format was organized as a theory presentation followed by participant discussion and reflection of practice for each of the five major content areas:

1. Rationale for implementing a palliative approach for patients with chronic disease.
2. Identifying patients who benefit from a palliative approach.
3. Assessment and planning components of a palliative approach.
4. Communication and advance care planning conversation.
5. Collaborative practice.

The content and process was captured in a PowerPoint presentation that provided the reference for the faculty leading the workshop. To maximize attendance, and based on advice of the key stakeholders, the organizers adopted a four-hour afternoon session format, following a provided lunch. Physicians were reimbursed for one session for attending and earned CME credits from the BC College of Family Physicians.

## **5. Developing Self Audit and Pre-Reading**

Drawing on the previous work and experience of the BC CDM Structured Collaboratives, a strategy of providing a self audit to participants prior to the workshop was adopted. The objective of the self audit was to enable practitioners to examine the care they have been providing to this group of patients prior to attending the workshop.

As no existing self audits were found that could be used in the workshop, self audits were developed as part of the workshop planning to reflect best practice of implementing a palliative approach in patients with advancing chronic illness. Two audits were developed: one focused on care of patients who had recently died from chronic illnesses, and the other focused on care of patients with advanced disease who the participant would not be surprised if the patients were to die in the next year. The self audits were sent out prior to the workshop (see Appendix 6).

The evidence to support the content for a palliative approach was drawn from the palliative care and chronic disease literature that has recently emerged. This strategy was adopted because, in contrast to the disease-modifying aspect of CDM, such as management of congestive heart failure and COPD, no existing Canadian clinical practice guideline specific to implementing a palliative approach in the care of patients with life-limiting chronic disease currently exists. Specific references from the palliative and CDM literature were provided to the participants for pre-reading (see Appendix 6) and as part of the handouts on the day of the workshop.

## **6. Identifying Teaching Faculty**

One of the goals of the Practice Support Program process is to identify faculty who are as much like the participants as possible. The two key faculty for the workshop were Dr Charles King, Family Physician and HPC Physician in WRSS, and Ms Della Roberts CNS, HPC WRSS, and FH CNS End of Life. Given Dr King's and Ms Roberts's clinical roles and relationships with the WRSS community of practice, it was determined that they would be perceived as credible clinicians familiar with the practice realities.

Additional faculty were Dr Doris Barwich, FH Medical Director HPC End of Life Care and Dr Douglas McGregor, Regional Medical Director HPC Vancouver Coastal Health. As experienced family physicians and given their medical leadership in both Fraser Health and Vancouver Coastal Health, they provided credibility to the workshop process and content. Ms Sue Grant, a nurse educator specializing in advance care planning, was contracted to provide the skills-based advance care planning conversation component of the workshop.

## **7. Inviting Participants**

Invitations were sent by e-mail to selected primary care providers in the community of practice in WRSS. In an attempt to meet the goal of improved communication and collaboration, both family physicians and other interdisciplinary team members were invited in approximately equal numbers. Invitations were sent to family physicians with the White Rock Division of Family Practice and other primary care practitioners who worked in the WRSS area (case managers in the Home Health Office; CD nurses in family practices; respiratory home services; the renal care coordinator; a clinical resource nurse in White Rock Hospice Palliative Care).

Additional practitioners outside the WRSS area were invited to build the complement of interdisciplinary providers (nurse practitioner working in Home Health Newton; nurse practitioner from a seniors' clinic in New Westminster; social worker from Fraser Valley Cancer Centre). Invitations were also extended to people in educational and decision-making roles involved with CDM and palliative care (Fraser Health Directors for Chronic Disease Management and Home Health; BCMA Practice Support Program Lead; and members of the Workshop Task Group).

In preparation for the workshop, the participants were requested to reflect on their own practice with the chronically ill patient population. The invitation noted that participants would be asked to complete some pre-workshop preparation. Registered participants were sent an e-mail listing three articles for pre-reading and a request to complete audits of five patients in their care (two who had died from chronic illness and three current patients with advanced disease).

## **8. Fostering Interprofessional Collaboration**

It was a surprise to discover that no previous workshops had brought this group of primary care providers together and that there was very little integration or collaborative practice except in instances where a CD nurse worked directly in a physician's office. Strategies were therefore developed to foster collaborative practice among the invited participants.

First, to ensure interprofessional discussion at the tables, participants were pre-assigned to tables. Each table was assigned two family physicians, two non-physician practitioners, one member of the Workshop Planning Subgroup, and one person in a decision-making or system role. Participants were given their table assignments at registration.

Second, to create an opportunity to practice "working" within an interdisciplinary team, participants were assigned to a triad at their table. Each participant's name tag had a colored dot, assigning them to one of two triads, which divided each table into interprofessional groups for interactive skills-based practice conversations.

Finally, the workshop design incorporated opportunities for table discussion of opportunities to improve collaborative practice specifically for shared patients with life-limiting chronic disease.

## **9. Delivering the Workshop**

The workshop was held on June 2, 2009, at the Coyote Creek Golf Course in Surrey. All participants introduced themselves at the beginning of the workshop. The room was large, providing opportunities for participants to circulate among the tables and to clearly see each other. The workshop content was primarily delivered by the five faculty members using a PowerPoint presentation with frequent opportunities for small group discussions.

Following is a breakdown of the primary providers who attended:

- Family physicians: 12
- Case managers: 3
- CD nurses: 3
- HPC resource nurses: 1
- Nurse practitioners: 2
- Respiratory therapist: 1
- Social worker: 1

Three leadership participants attended:

- Dr Brenda Hefford, FH Physician Executive Lead for Primary Care
- Ms Lisa Kallstrom, BCMA Practice Support Program Lead
- Ms Michelle Medland, Project Coordinator Primary Care & Chronic Disease Management

Eight faculty and members of the Workshop Planning Task Group attended, as follows:

- Dr Doris Barwich
- Dr Douglas McGregor
- Dr Neil Hilliard
- Dr Charles King
- Dr Chris Rauscher
- Ms Pat Porterfield
- Ms Della Roberts
- Ms Sue Grant

Two support people attended to help with last-minute details, registration, liaison with the site, and minute taking. All participants who had registered for the workshop attended the session, with the exception of two family physicians and one invited leadership participant.

One member of the Workshop Planning Subgroup was assigned to each table and asked to record the table discussions and note the engagement of the participants in the discussion and content. Some Workshop Planning Subgroup members took a facilitation role at their tables; others acted more in the role of observer.

A handout (part of Curriculum package) was given to the participants to support their learning and engagement in the workshop process. During the first half of the workshop, participants were



asked to work in dyads at their tables for the discussion sections. In practice, many of the tables chose to hold these discussions among all table participants. The groups worked in triads for the advance care planning practice session. The final discussions about collaborative practice were held among the full table, or triads at the table.

Feedback from the participants was collected at the end of the Workshop.

## Key Findings

Three sources of information were used to identify key findings related to the workshop:

1. Recording of the proceedings.
2. Evaluation of the workshop by participants (see Appendix 4).
3. Workshop debriefing meeting of the Workshop Planning Subgroup and decision makers.

The proceedings were recorded by members of the Workshop Planning Subgroup who were each assigned to a participant table. Their primary role was to observe the effectiveness of the workshop process and content as well as to take notes about the discussion at the tables. In addition, each table gave a verbal report that summarized the discussion at that table and notes were taken of this information. Both types of notes were included in the recording of the proceedings of the day. Input was also captured through an evaluation form completed by workshop participants.

A post-workshop debriefing session was held on June 9 with the members of the Workshop Planning Subgroup (including those who presented at the workshop and those who facilitated and recorded the table discussions); Dr Brenda Hefford, FH Physician Executive Lead for Primary Care; and Ms Sue Grant, the advance care planning consultant. The debriefing session systematically considered:

- The goals and objectives of the workshop and whether they had been met.
- Overall general comments on the workshop.
- General topics such as faculty, location, and participant mix.
- Review of specific elements such as the self audit tools, pre-reading, and handout packages.
- The curriculum package in relation to the objectives for each section.

The aim was to integrate and capture feedback recorded on the day of the workshop. Notes were taken of the discussion to capture the perspective of various members.

The key findings are discussed below and are organized to reflect input from two groups: the primary care provider participants and the workshop planners and decision makers.

### ***Feedback from Primary Care Provider Participants***

#### **Workshop Evaluation Results**

Twenty-four participants completed the evaluation form: 12 physicians, 3 case managers, 3 three CD RNs, 2 nurse practitioners, 2 social workers, and 2 who indicated "other" or who did not respond. The results are summarized below; a more detailed summary of the results appears in Appendix 5. Given the similarities between the ratings by physicians and other participants, the groups were analyzed together.

The evaluation indicates the workshop topic was viewed by all participants as an important and worthwhile subject and that getting together with other community-based providers was helpful. The findings indicate that participants are clearer about the need to consider a palliative approach

for certain patients and how to identify those patients as an outcome of the workshop. However, participants are less clear on who from the team they can work with in the care of these patients and their ability to support patients throughout the trajectory. The evaluation also identified some system issues (beyond the learning needs of primary care providers) that will need to be addressed to improve the care of this patient group.

The ratings on the individual sessions in the workshop ranged from 75% to 88% either agreeing or strongly agreeing that they were satisfied with the sessions. The highest rating (88% agreeing or strongly agreeing that they were satisfied) was given for identification of patients, and the lowest rating (75% agreeing or strongly agreeing that they were satisfied) for collaboration in care planning.

The majority of respondents indicated they would be able to practise more effectively in the areas addressed in the workshop. Identification of patients received the highest rating with 91% (22) either agreeing or strongly agreeing that they felt more confident they could practise more effectively. The lowest rating was received related to engaging in planning using existing resources with only 58% (14) either agreeing or strongly agreeing they could practise more effectively. The next lowest rating of 62% (15) (agreeing or strongly agreeing) was received in relation to participants' confidence at supporting patients throughout the trajectory. These two findings are indicative of concerns or uncertainty about operationalizing the care delivery that supports a palliative approach for the identified patients.

In the overall ratings of the workshop, 83% (20) agreed or strongly agreed that the workshop met the stated objectives and 79% (19) indicated they would practise differently when they returned to work. Almost 30% (7) of the participants indicated there was not enough time for discussion and interaction.

Three main themes emerged in response to the question: "What are the two most important things learned?"

1. Collaboration (i.e., team approach, networking, learning about and using resources).
2. Recognizing the importance of starting palliative care earlier and how to identify patients (e.g., surprise question).
3. Communication around EOL discussions and advance care planning including tools to talk to patients.

The participants were asked to comment on the workshop and the following suggestions for revision were given:

- Reduce the didactic/lecture portion of the workshops.
- Increase time on interaction with other providers (other community providers, GPs, and specialists), case discussions, and group discussions.

The participants also suggested including a more practical follow-up session on planning how to take what they learned back to practice, specific tools and flow sheets to support the practice change, and specifics on how the team would work together.

## **Key Themes from Participant Contributions**

The notes taken of participant contributions on the day of the workshop were reviewed. A more detailed summary of the discussion is contained in Appendix 5. The discussion on care and collaborative practice revealed themes that may be useful to future planning and system development. The suggestions for changes were grouped into themes; some examples from the participants are provided here:

Areas identified for potential improvement:

- Identifying patients: each practice could code the same; develop checklists to identify early; case manager could identify patients and call GP.
- Clarifying care resources: need clarity on referral criteria (i.e., who will be identified to work with the GP); need role clarity and access to support for patients identified.
- Building the team and working together: could build "permanent" teams with one or two community staff linked to GP offices; perhaps the CD RN could be the link; clarify the "case manager."
- Communication: linking health records; consider how to better link "team" by phone.

## ***Feedback from the Workshop Planning Subgroup and Decision Makers***

Minutes of the debriefing session were taken and then subsequently reviewed. These following comments reflect feedback on overall issues and were quite similar to feedback received from workshop participants:

1. Participants in the workshop seemed to recognize a need and were motivated to change care for this group of patients.
2. It is important to carefully consider the particular community context in determining who to invite and to identify the extent to which they are functioning in a collaborative way and to increase the collaborative and team-building focus in the workshop.
3. The suggestion was to start the theme of collaboration at the start of the workshop, not the end (i.e., integrate throughout); the workshop did get participants thinking about collaborative practice.
4. Too much material: need to decrease content and increase participation.
5. Decrease number of presenters to increase flexibility of content and timing.
6. Need to consider how to manage different learning needs of GPs (e.g., billing codes) and others
7. Facilitators are key: one at each table to ensure discussion and model collaboration; ideally have a local practitioner facilitate.
8. There was discussion regarding the extent to which WRSS was a unique community of practice and if the workshop would need to be adapted (and how) for other groups.
9. It was suggested that references to cancer be excluded in the pre-reading and self audits so that the focus is clearly on patients with life-limiting chronic disease. It was felt that the audits were useful both to get participants thinking and to model good practice. Although not all participants completed the self audits, the evaluation results show that they were an effective tool for reflection. The self audits were not summarized as planned in the strategies for Objective 1 as the decision was made during the planning stages to make submission of the self audit forms optional and none were handed in (see Appendix 3).

# Key Outputs

- 1. Preparation of the Phase 2 report**
- 2. Preparation of the final Palliative Approach to Chronic Disease Workshop Curriculum Package ( Appendix 6)**

Based on the combined feedback from participants at the July 9 debriefing session and participants in the workshop, the Palliative Approach to Chronic Disease Management Workshop curriculum package was revised to incorporate feedback and provide input in the following key areas:

1. The facilitators' guide has been revised to include an engagement strategy as an important aspect of planning the workshop, including considering the appropriate community-based providers to invite to the workshop and identifying their specific needs.
2. As the concept of CDM patients needing a palliative approach to care is new, discussions will need to occur prior to the workshop to identify how the community of practice is organized in relation to the community-based providers who collaborate with caring for these patients along with the GP.
3. The flow of the workshop has been revised to emphasize collaboration and team building at the beginning and as a theme throughout the workshop rather than only a content focus for one portion of the workshop.
4. To build further collaborative practice, rather than asking the participants to work in dyads for discussion, full table discussion has been adopted as the interaction strategy except for the communication practice skill component.
5. Recognizing the importance of meeting the needs of participants, a table discussion to identify what participants hope to get out of the workshop has been incorporated at the beginning.
6. Content areas suggested by the GP focus groups and literature were validated by the key findings. However both the participants and the Workshop Planning Subgroup indicated less time should be given to lectures and more time on interactive activities. The workshop has been revised to reflect this direction.
7. To support participants to translate the workshop learning into practice, completion of a specific action plan by the participant at the end of day has been incorporated into the curriculum plan.
8. In the communication and advance care planning conversation section, the practice scenarios have been modified to more closely reflect challenging communication situations and to allow the participant to select the scenario they wish to practice.
9. Description of two case examples of the patient population have been integrated into the curriculum at the beginning of the workshop as a strategy to more quickly engage the participants with the focus of the session.
10. To support the key points for learning, the participant handout has been modified and now includes a reference page for each of the main components of the workshop content.
11. The handout package has been streamlined to focus only on chronic illness and references to the oncology population were removed.

**For the full curriculum package contact BCHPCA <http://www.hospicebc.org/>**

## Summary and Recommendations

This project sought to build capacity for improving the care of patients with life-limiting chronic illness at the end of life, and to support the implementation of a palliative approach in the care of these patients by primary care providers. The strategy to meet these objectives was to develop, conduct, evaluate and refine a specifically designed workshop for primary providers who work with patients with chronic disease in a geographic community of practice. The value of the collaborative workshop 'Palliative Approach to Chronic Disease Management' in building the awareness of the need for a palliative approach and in enhancing identification, assessment, communication and care planning with CD patients was validated by the participants of the workshop held on June 2, 2009.

The experience of the project Task Group, the results of the project, and feedback from workshop participants, have culminated in a number of recommendations. These recommendations address the following areas: building system capacity, creating practice supports, and utilizing the workshop curriculum to support the implementation of a palliative approach in the care of patients with life-limiting chronic illness by primary care providers throughout British Columbia. The recommendations were developed for decision makers in Primary Care, Chronic Disease Management, Home and Community Care, and Hospice Palliative Care.

### **Recommendations 1-5: Building System Capacity for a Palliative Approach**

Participants of the workshop emphasized that system changes were required in order to enable primary providers to more fully implement a palliative approach in CDM, a finding that echoed similar feedback received during the strategic planning process undertaken by the MoHS in the fall of 2008.

The palliative approach for people with life-limiting chronic disease necessitates different clinical approaches and partnerships between primary care teams (including GPs and community-based providers), specialists providing CDM, and experts in hospice palliative and EOL care to address the EOL care needs for this population. The recognition of the palliative care needs of the population with chronic illness is relatively recent, and community-based systems in particular need to consider the best way to orient services to meet these needs.

1. Ensure that the palliative approach to care for the patients with an advance illness trajectory is a joint responsibility of involved program leaders and practitioners in Primary Care, Chronic Disease Management, Home and Community Care and Hospice Palliative Care. This will mean more clearly defining existing relationships and developing new relationships around the care of these patients.
2. Explore and clarify issues related to the roles and responsibilities of all community-based providers who may collaborate with the family physician in the care of these patients. The palliative care approach requires effective communication between care providers to avoid duplication and gaps in care and a proactive and continuous (not episodic) collaborative model of care.

3. Work with the key stakeholders to clearly define the services available from specialized palliative care programs in relation to patients with life limiting chronic illness and communicate these to primary providers working with CDM patients.
4. Use the Palliative Approach in CDM Workshop as a venue to strengthen relationships and create effective interface between all sectors and providers involved in the care of patients with life limiting chronic illness.
5. Strengthen and foster effective collaboration and partnership among HPEOL educational providers and existing educational initiatives (e.g., UBC inter-professional course; Victoria Hospice intensives, and regional educational opportunities) and education offered within chronic disease and primary care initiatives.

### **Recommendations 6-8: Creating Practice Supports for a Palliative Approach**

Practice supports aimed at enhancing inter-professional, collaborative practice in the implementation of a palliative approach in CDM are required. The supports must acknowledge the integral role of the family physician as well as other primary care providers, as well as the realities of the chronic illness trajectory and the need to develop access to effective and integrated community and home-based options for care.

The GPSC has assumed responsibility for the development of the resources to support practice changes in GP offices. If collaborative care approaches are to be supported, specific practice initiatives for other providers (e.g., CD nurses, Nurse Practitioners and home and community care staff) will be needed and will need to be linked to the practice changes being developed for GPs.

6. Identify the supports that can be accessed (educational sessions, practice tools, and specialist consultation from experts in EOL care) to support the primary care providers (GPs and other community-based providers) who provide this care.
7. Develop specific practice tools to support care of this population group by various members of the interdisciplinary team. Examples include integrating components of a palliative approach within the flow sheets for care of disease-specific groups such as COPD and congestive heart failure patients.
8. Identify methods to improve sharing of client care information between providers caring for this population.

### **Recommendations 9-11: Utilizing the Workshop Curriculum**

The Palliative Approach in CDM Workshop curriculum has been revised based on the feedback received from workshop participants, the Workshop Planning Subgroup, and decision makers who attended the workshop to ensure that the curriculum can be easily used for other interdisciplinary groups throughout the province. The BCHPCA Learning Centre for Palliative Care will partner with the MoHS, health authorities, UBC and others to ensure access to the Palliative Approach to CDM Workshop for providers throughout British Columbia and Yukon. In this work, it is recommended:

9. Provide workshops throughout British Columbia using the curriculum developed through this project for interdisciplinary groups of primary care providers as a strategy to support more collaboration in the implementation of the palliative approach to patients with life-limiting chronic illness.
10. Create capacity for delivery and uptake of this curriculum by training and mentoring local champions and developing resources for ongoing support of the palliative approach to care.
11. Develop faculty and identify financial resources to support sustainable education in the palliative approach to care throughout British Columbia.

With the conclusion of this project, the CSCC BC/Yukon will have completed their planning role and will transition this work to the BCHPCA Learning Centre for Palliative Care whose role will be to work with the health authorities, the MoHS, and other stakeholder organizations. One of the first actions for the BCHPCA Learning Centre will be distributing this report and recommendations to key end-of-life policy makers and planners in the MoHS, the BCMA, the GPSC, and health authority planners and clinicians with responsibility to develop better integrated hospice palliative care EOL services across the health care continuum.



## References

- BC Ministry of Health Services. (2007). Primary Health Care Charter: A Collaborative Approach [http://www.primaryhealthcarebc.ca/library/publications/year/2007/phc\\_charter.pdf](http://www.primaryhealthcarebc.ca/library/publications/year/2007/phc_charter.pdf).
- BC Ministry of Health Services. (2006). A Provincial Framework for End-of-Life Care in British Columbia. <http://www.health.gov.bc.ca/library/publications/year/2006/framework.pdf>
- Bern-Klug, Mercedes. (2004). The Ambiguous Dying Syndrome. *Health & Social Work*, 29(2): 55-65.
- Brazil, Kevin et al. (2007). Building Primary Care Capacity in Palliative Care: Proceedings of an Interprofessional Workshop. *Journal of Palliative Care*, 23(2): 113-116.
- Canadian Hospice Palliative Care Association. (2002). A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Figures #7 and #10. [www.chpca.net](http://www.chpca.net)
- Canadian Institute for Health Information (2008). *Health Care Use at the End of Life in British Columbia*. Ottawa: CIHI. [http://secure.cihi.ca/cihiweb/en/downloads/EOL\\_Report\\_BC.pdf](http://secure.cihi.ca/cihiweb/en/downloads/EOL_Report_BC.pdf)
- Curran, Vernon. (2004) Interprofessional Education for Collaborative Patient-Centered Practice Research Synthesis Paper. Memorial University Interprofessional Education for Collaborative Patient-Centered Practice Initiative. <http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/interprof/synth-eng.php>
- Curtis, J. Randall et al. (2001). Understanding Physicians' Skills at Providing End-of-Life Care. *Journal of General Internal Medicine*. 16: 41-49.
- Groot, M. and Vernooij- Dassen, M. (2005). General Practitioners (GPs) and Palliative Care: perceived tasks and barriers in daily practice. *Palliative Medicine*. 19:111-118.
- Guidelines Advisory Committee. (2008). Palliative Care: Recognizing Eligible Patients and Starting the Discussion. Ontario GAC Reference #260. Endorsed Date: September, 2008. [www.gacguidelines.ca](http://www.gacguidelines.ca)
- Hutchinson, Tom A. (2005). Transitions in the Lives of Patients with End Stage Renal Disease: A cause of suffering and an opportunity for healing. *Palliative Medicine*. 19: 270-277.
- Lorenz, Karl A. et al. (2008) Evidence for Improving Palliative Care at the End of Life: A systematic review. *Annals of Internal Medicine*. 148(2): 147-159. [www.annals.org](http://www.annals.org)
- Lynn, Joanne. (2005). Living Long in Fragile Health: The new demographics shape end of life care. *Improving End of Life Care: Why has it been so difficult? Hastings Center Report Special Report*. 35(6): S 14-18.
- Murray, C.J.L. and Lopez, A.D. (1997). Alternative Projections of Mortality and Disability by Cause 1990-2020: Global burden of disease study. *Lancet*. 349(9064): 1498-1504.

- National Gold Standards Framework Centre. (2008). UK NHS End of Life Care Programme. The Gold Standards Framework: Prognostic Indicators Guidance to aid identification of adult patients with advanced disease, in the last months/year of life, who are in need of supportive and palliative care.
- National Institutes of Health. (2004). NIH State-of-the-Science Conference Statement on Improving End-of-Life Care. NIH Consensus and State-of-the-Science Statements. 21(3).
- Palliative Care Australia. (2005). A Guide to Palliative Service Development: A population based approach. PCA, Canberra.  
<http://www.palliativecare.org.au/portals/46/resources/PalliativeCareServiceDevelopment.pdf>
- Shipman, Cathy et al. (2008). Improving Generalist End of Life Care: National consultation with practitioners, commissioners, academics, and service user groups. *British Medical Journal*, 337(a1720): 1-8.
- Statistics Canada. (2001). Population Projections for Canada, Provinces & Territories 2000- 2026. Catalogue #91-520, 124.  
<http://dsp-psd.tpsgc.gc.ca/Collection-R/Statcan/91-520-XIB/0012691-520-XIB.pdf>
- Stuart, Brad. (2003). Transition Management: A New Paradigm for Home care of the Chronically Ill Near the End of Life. *Home Health Care Management & Practice*. 15(2): 126-135.  
<http://www.sagepublications.com>
- Turris, Mark and Rauscher, Chris. (2005). Palliative Trajectory Markers for End-Stage Heart Failure. Or [Oh Toto. This Doesn't Look Like Kancerous!]. *Canadian Journal of Cardiovascular Nursing*. 15(2): 17-25.
- Wenger, Neil S., and Rosenfeld, Kenneth. (2001). Quality Indicators for End-of-Life Care in Vulnerable Elders. *Annals of Internal Medicine*. 135(8): 677-685.
- World Health Organization. (2003). WHO Definition of Palliative Care.  
[www.who.int/cancer/palliative/definition/en/print.html](http://www.who.int/cancer/palliative/definition/en/print.html)
- Zhang, Baohui et al. (2009.) Health Care Costs in the Last Week of Life: Associations with end-of-life conversations. *Archives of Internal Medicine*. 169(5) 480-488

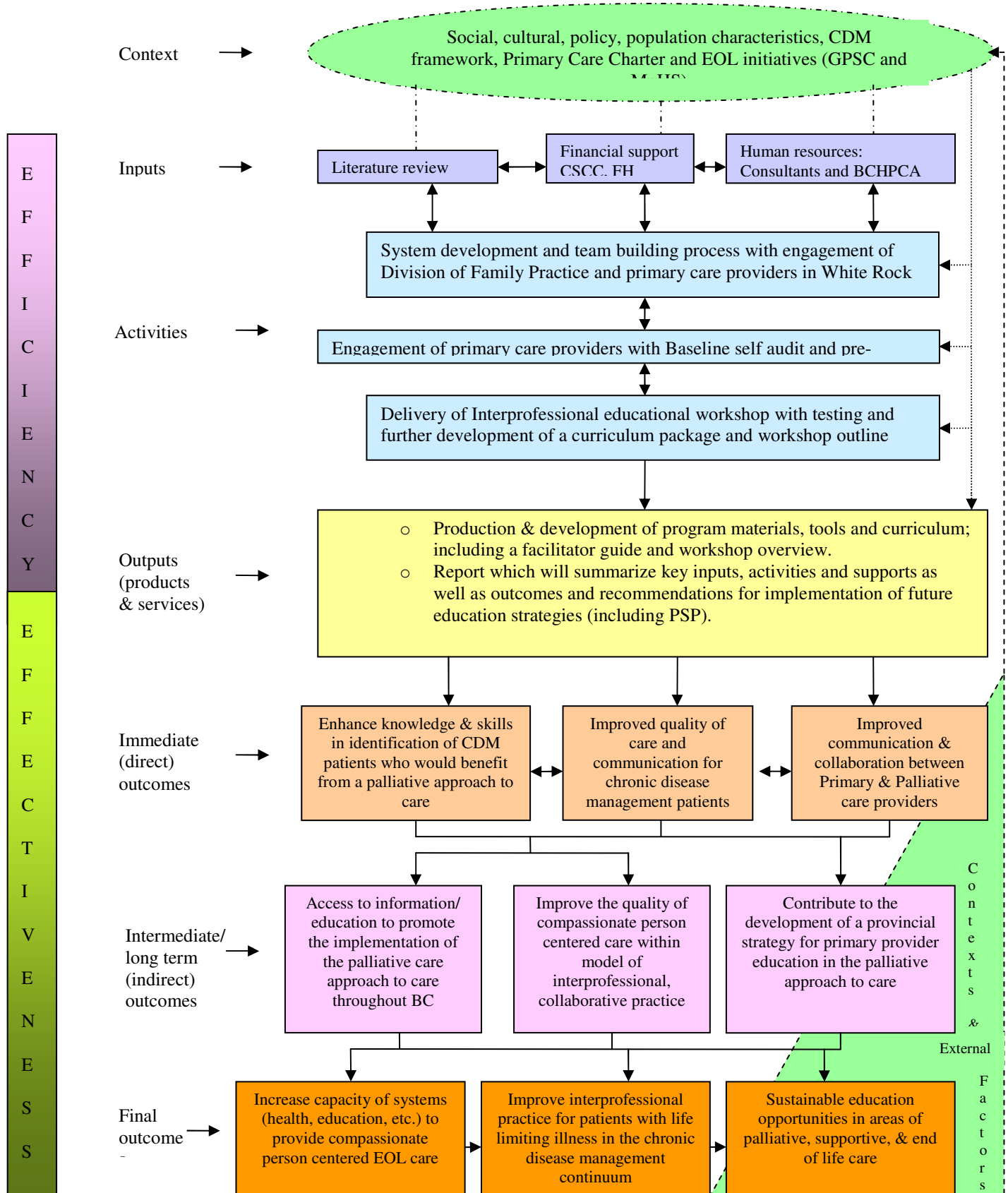
# Acknowledgments

## Hospice Palliative End of Life (HPEOL) Education Working Group

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The Task group would also like to acknowledge the significant support provided by Ms Jo Wearing in the preparation of the Phase 2 report.

# Appendix 1: Logic Model April 30, 2009



## Appendix 2: Invitation to the Workshop



# *Palliative Care Approach for Patients with Advanced Chronic Disease: A practice based workshop*

For family physicians and primary care professionals

**Tuesday, June 2, 2009**

**Coyote Creek Golf Course, 7778 – 152<sup>nd</sup> Street, Surrey**

### THE WORKSHOP WILL ENABLE YOU TO IDENTIFY:

**WHO** would benefit from palliative approach in care?

**WHY** it is important to identify patients early

**HOW** you can implement the palliative approach

**WHEN** to refer to specialized palliative care services and HPC consultation

**WAYS** to more effectively collaborate with others to plan care

1230	Lunch	
1300	Palliative Approach: Context	Dr Barwich
1345	Identifying Patients	Dr McGregor
1405	Assessment, Planning	Dr King
1445	Break	
1500	Communication	Dr Barwich
1515	ACP Conversations	Sue Grant
1615	Collaborative practice	Della Roberts
1645	Next Steps	Dr Barwich

## Appendix 3: Planning Document: Strategies to Achieve Workshop Objectives

1. Establish a baseline regarding current practice in primary care for patients with chronic life-limiting disease by various primary care providers.
  - Strategy:
    - Phase 1 summary report.
    - Participant completion of a self audit of current patients in their practice and a retrospective look at management of recent deaths prior to attending the workshop.
    - Summary of the participant self audits post workshop.
    - Summarize themes from the workshop record of participant discussion of current practice in the workshop.
2. Engage primary care providers in the White Rock/South Surrey area and promote collaborative practice in the provision of a palliative approach.
  - Strategy—Participants Invited
    - Invite participants from a community of practice—White Rock Integrated Health Network: Division of Family Practice; Chronic Disease Nurses; Home Health Case Managers; Renal Care Coordinator.
    - Invite important interdisciplinary members that are not yet a part of the community of practice White Rock IHN: Nurse Practitioner (New West); Social Worker (FVCC).
    - Invite HPC Team members from the WR community to promote relationship and referral: Clinical Resource Nurse; Palliative Care Physician; CNS.
  - Strategy—Include content about collaborative practice and interactive skills based process to reflect theory.
    - Use the Mentoring Primary Health Care Teams in Collaborative Palliative Care Practice Learning Module March 2008, as a reference for content and teaching process.
  - Strategy—Use an interactive interdisciplinary process as a teaching strategy within the workshop
3. Identify why it is important to identify patient's early (improved outcomes).
  - Strategy—Theory (presented at beginning and thread)
    - Context.
    - Patients who are sick enough to die vs. certain to die.
    - Improved outcomes (Health Care Costs in Last Weeks of Life Associations with End of Life Conversations Arch Intern Med. 2009; 169(5)(480-488). Zhang, Baohui, et al.
    - Patient barriers to ACP (84% perceived to be irrelevant—although 70% reported fair to poor health and more than 1/3 had previous admission to ICU) —JAGS 2009(57):31-39. A clinical framework for improving the advance care planning process: start with patient's self-identified barriers. Schieckedanz, Adam et al.
  - Strategy—Awareness/Attitude/Practice
    - Self reflection of recent patient deaths and outcomes vs. optimal.
4. Identify those patients in their practice with chronic disease who would benefit from a palliative approach in care (integrate the palliative approach to care with disease modifying therapies and improve patient and family satisfaction and outcomes).
  - Strategy—Theory base
    - Key transitions and support needs in the trajectory of illness (McGregor/Porterfield Model).
    - Identification tools—to identify those "sick enough to die" —UK.

- Sentinel events—ER visits; hospitalization; weight loss; (Gold Standard prognosis reference).
5. Identify patients who would be appropriate to refer for specialist palliative care consultation and service and know HPC consult access.
    - Strategy—Description of HPC program and criteria
      - Consultation
      - HPC service—Home Health; Hospice Residence; Tertiary Care
  6. Become familiar with assessment and care planning tools and resources that will support implementing a palliative approach.
    - Strategy—Use UK model—identification; assessment; care planning as framework
    - Strategy—Theory
      - Transitions GP Model for EOL Care
      - Self audit tool
      - References provided in pre-reading
    - Strategy: Self Audit Discussion
  7. Tools to use to assess and monitor the supportive/palliative needs of patients with chronic disease throughout the trajectory of illness. Edmonton Symptom Assessment Scale and Palliative Outcome Scale.
    - Care Planning: Review the referral resources linked to transition points along the palliative care continuum.
  8. Enable the initiation of advance care planning conversations
    - Strategy:
      - Know how to assess patient/families understanding of illness and key times for review and education re key transitions.
      - Identify the information and care planning needs of patients and families.
      - Explore and practice skills to initiate conversations that address goals of care throughout the trajectory of care.
      - Disease-specific ACP conversations.
      - Maximizing team roles in identifying readiness and participating in ACP conversations.
  9. Explore the barriers (emotional and practical) to practice to incorporate a palliative approach and the possible strategies to address these.
    - Strategy:
      - Identify through all discussion emotional and practical barriers and record these to bring forward during a focused discussion.
      - For physicians—provide information about billing codes that outlines how they can be paid to do this work.
      - Discussion collaboration as a strategy to maximize patient benefit and minimize the work of one provider.
  10. Identify learning needs of interdisciplinary team members that are the same or distinct from family physicians/general practitioners.
    - Strategy:
      - Pre-work or upon registration.
      - Record the learning needs identified throughout the discussion—have one recorder designated for this role.
      - Identify the discipline that raises the learning need.
  11. Teach in an interactive, practice, and skill- based interdisciplinary style

# Appendix 4: Workshop Evaluation Form

## Primary Care Palliative Approach Workshop

*Please take a few minutes to assist us in evaluating this event*

**Based on a 5-point scale: 1 = Strongly Disagree; 2 = Agree; 3= Neutral; 4= Agree; 5 = Strongly Agree**

**Please indicate your level of agreement with the following statements:**

1) I have greater understanding of the Palliative approach to care.	1	2	3	4	5
2) I am satisfied with the quality, content and presentation of the following: Workshop Sessions:	1	2	3	4	5
Overview of Palliative/End-of-Life care	1	2	3	4	5
Trajectories and Transitions in Palliative Care	1	2	3	4	5
Identification of patients for the palliative approach	1	2	3	4	5
Assessment of patients for the palliative approach	1	2	3	4	5
Care planning	1	2	3	4	5
Conversations in Care and Advance Care Planning	1	2	3	4	5
Self Audit tool	1	2	3	4	5
Syllabus	1	2	3	4	5
3) I feel more confident in that I can more effectively:					
Identify patients for implementation of the palliative approach	1	2	3	4	5
Assess patients for their care and support needs	1	2	3	4	5
Engage in care planning that utilizes existing resources	1	2	3	4	5
Initiate conversations that identify the patient's goals of care	1	2	3	4	5
Support patients and families throughout the trajectory of illness	1	2	3	4	5
4) Overall this workshop,					
Met stated objectives	1	2	3	4	5
Had practical application and relevance for my practice	1	2	3	4	5
Allowed enough time for discussion and interaction	1	2	3	4	5
Provided opportunities for networking/relationship building	1	2	3	4	5
5) Based on what I learned at this workshop, it is very likely that I will "do things differently" when I return to my work.	1	2	3	4	5

- |   |   |
|---|---|
| <p>6) What are the two most important things you have experienced/learned at this workshop?</p> <p>1. ....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>2. ....</p> <p>.....</p> <p>.....</p> <p>.....</p> | <p>7) What two things will you do differently as a result of what you have learned?</p> <p>1. ....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>2. ....</p> <p>.....</p> <p>.....</p> <p>.....</p> |
|---|---|



I am a: Case Manager  CDM nurse  MD  Nurse Practitioner  Social Worker  Other: \_\_\_\_\_  
I work in a: Solo/Group Practice  Multidisciplinary setting  Home Health setting  Other: \_\_\_\_\_

Do you have any other comments, suggestions for improvement and/or topics for future workshops?

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Thank you for participating!

# Appendix 5: Detailed Results from Workshop Participants

## The Evaluation Form

Twenty-four participants completed the evaluation form: 12 physicians; 3 case managers; 3 CD RNs; 2 nurse practitioners, 2 social workers, and 2 who indicated "other" or did not respond. Twelve participants worked in solo/group practice; 4 in a multidisciplinary setting; 14 in home health; and 5 indicated "other" or did not respond. The totals for work setting exceed the respondent numbers as some had multiple responses.

The quantitative results are summarized below for the 24 respondents. The detailed results for the combined group of participants and a breakdown of the results separated by physicians and all others are available from the Workshop Task Group. The ratings between the two groups were generally comparable although there were 5 "disagree" ratings (rating 2) and 28 "neutral" ratings (rating 3) from MDs and 18 "neutral" ratings from the "other" group. In addition there were more "no response" ratings from the "other" group. The five "disagree" ratings (rating 2) related to three specific aspects of the workshop (the session on collaborative care planning, confidence in engaging in care planning using existing resources, and allowing time for discussion and interaction).

A recalculation was done removing those who did not respond to a question and looking at percent calculations for the physicians as a group versus others as a group. The general rating trends were similar and therefore the ratings were analyzed for all respondents together.

**Note:** There is a typographical error in the workshop evaluation form. The evaluation form used a 5-point scale with "strongly disagree" rated as 1 and "strongly agree" rated as 5. The second rating on the scale was incorrectly labeled "agree" rather than "disagree" and that was followed by a neutral rating for three. This means that some participants may not have followed the 5-point likert scale in making their ratings.

## Quantitative Results

- **Greater understanding of the palliative approach to care:** 58% (14) participants agreed, 29% (7) strongly agreed, and 3 did not respond.
- **Quality, content, and presentation of the workshop sessions:** The ratings related to the six sessions ranged from 50% to 63% agreeing they were satisfied and from 21% to 38% strongly agreeing they were satisfied. One to three participants provided a neutral response in rating each of the six sessions, and 38% (9) of participants strongly agreed that they were satisfied by the session on identification of patients.
- **Self audit tool:** Five participants (all physicians) gave a neutral rating for the self audit tool, 38% (9) of participants gave an agree rating for the self audit tool, and 25% (6) of participants gave a strongly agree rating.
- **Ratings on ability to practise more effectively:** The majority of respondents agreed they would be able to practise more effectively in the areas addressed in the workshop. Identification of patients received the highest rating with 91% (22) either agreeing or strongly agreeing. The lowest rating was received related to engaging in planning using existing resources with 58% (14) either agreeing or strongly agreeing they could practise more effectively, and 33% (8) giving a neutral or disagree rating. The next lowest rating of

62% (15) (agreeing or strongly agreeing) was received in relation to participants' confidence at supporting patients throughout the trajectory.

## Overall Ratings

In the overall ratings of the workshop, 83% (20) agreed or strongly agreed that the workshop met the stated objectives, and 79% (19) indicated they would practise differently when they returned to work. Almost 30% of participants (7) indicated there was not enough time for discussion and interaction.

The remaining questions were analyzed to look for common themes. The comments for physicians and others were first reviewed separately. As the same themes emerged, the comments were combined and analyzed together.

Three main themes emerged in response to the question: What are the two most important things learned?

1. Collaboration (i.e., team approach, networking, learning about and using resources).
2. Recognizing the importance of starting palliative earlier and how to identify patients (e.g., surprise question).
3. Communication around EOL discussions and advance care planning including tools to talk to patients.

Respondents were asked to identify what two things they would do differently. The following themes were identified:

- Start identifying patients (e.g., use surprise question, develop a list).
- Increase discussion with patients and pay attention to EOL/advance care planning.
- Look for resources and collaborate (e.g., get a CD RN; use community resources and specialty services).
- Improve skills (e.g., take more courses; use the tools provided).

The respondents were asked to comment on the workshop and the following themes emerged:

- Reduce the didactic/lecture portion of the workshops
- Increase time on interaction with other providers (other community providers, GPs, and specialists), case discussions, and group discussions
- Workshop organized and informative

Two comments related to system issues were identified from non-MD providers: 1) A concern with identifying populations when there are no community resources to support them; 2) confusion regarding the role of the case manager and the emergence of other "case managers" is confusing to clients/families.

Objective 9 of the workshop (see Appendix 3) set out strategies that would permit the identification of learning needs and determine if the needs of other members of the team are the same or distinct from family physicians/GPs. It was planned that this would be accomplished based on participant discussions over the course of the workshop. This information did not arise during the afternoon's discussion. The comments from the workshop evaluation form were

reviewed to look for learning needs. Several themes were identified. The learning needs identified were similar between MDs and others:

- Need to get to more practical next steps in a follow-up session (e.g., examples of providers doing this; planning how to take back to practice; specifics on how the team can work together).
- More information needed on resources that are available and specific tools/flow sheets to support this practice.

### **Key Themes from Participant Discussion on the Day of the Workshop**

The notes taken of participant contributions on the day of the workshop were reviewed. The participants identified areas that were working well and some areas that need improvement. The discussion related to care and collaborative practice revealed themes that may be useful to future planning and system development.

#### **What is working?**

- Practice-based CD RNs free up GP time.
- Trust builds when we work closely together.
- The new nurse practitioner roles are helpful.
- Have the advance care planning conversation, and then refer to the MD for more conversation—this works well.

#### **Issues identified**

- Need better linkages between GPs and Fraser Health programs.
- Home Health central intake—referrals too difficult/complex.
- Need a list of who is doing what.
- Need improved communication between case managers and GPs.
- Lack of GPs doing home visits to this group.
- Patient identified but may have no GP.
- CD RNs have huge case loads.
- Not all patients have a CD RN.

#### **Identifying patients**

- Surprise question, sentinel events, and choice criteria are useful.
- Doctors are using the annual chronic illness review as a time to address goals of care.

A number of comments related to 1) what is next, once patient is identified, and 2) concerns about dealing with the patient's anxiety.

#### **Care and collaboration**

Areas identified for potential improvement:

- Identifying patients (e.g., each practice could code the same; develop checklists to identify early; case manager could identify and call GP; review how the practice currently handles this; develop a palliative flow sheet).
- Clarifying care resources (e.g., need clarity on referral criteria—who will be identified to work with the GP; GP could let go of some roles to others; need role clarity and access to support for patients identified).
- Building the team and working together (e.g., could build “permanent” teams of one to two community staff linked to GP offices; perhaps the CD RN could be the link; CD RN in GP office is very helpful; clarify the “case manager”).
- Communication (e.g. develop better ways of communicating with the “team”; linking health records; consider how to better link “team” by phone).

## Appendix 6: Curriculum Package Outline

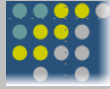


Curriculum Package

*The Palliative Approach to Chronic Disease Management*

August 4, 2009

**Full curriculum package contact BCHPCA <http://www.hospicebc.org/>**



# The Palliative Approach to Chronic Disease Management Workshop

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**Full curriculum package contact BCHPCA <http://www.hospicebc.org/>**

The **Palliative Approach to Chronic Disease Management Workshop** is designed to assist primary care providers to integrate a palliative care approach with chronic disease management (CDM) in the care of patients who have a life-limiting illness. The **goal** of the workshop is to improve the quality of care for CDM patients by: improving communication and collaboration in the identification, assessment, communication, and care planning for CDM patients who could benefit from a palliative approach to care.

### **Workshop Objectives**

1. Engage primary providers working with patients with chronic diseases or advanced illness who would benefit from a palliative approach.
2. Promote collaborative practice in the provision of a palliative approach in CDM.
3. Identify patients with chronic disease who would benefit from a palliative approach.
4. Identify & become familiar with assessment and care planning tools and resources that support implementing a palliative approach.
5. Enable the initiation of advance care planning conversations.
6. Identify patients appropriate to refer for specialist palliative care consultation and service, and know how to access those services.

### **Credits Available**

June 2009 workshop approved by College of Family Physicians of Canada for 3.5 National M1 credits.

### **Acknowledgements**

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Leadership was provided by a Task Group of the BC/Yukon CSCC Education Working Group in partnership with the BC Hospice Palliative Care Association's (BCHPCA) Learning Centre for Palliative Care. The Workshop Task Group was led by Dr Doris Barwich, Medical Director of End of Life Care in Fraser Health and Chair of the BCHPCA Learning Centre for Palliative Care and the BC/Yukon CSCC Education Working Group.

The following were members of the Workshop Task Group:

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- Dr Neil Hilliard, Palliative Care Physician, Fraser Health Hospice Palliative Care Program and Lead for the Palliative Care Guideline Development Project, BCCA Family Practice Oncology Network
- Dr Peter Kirk, Head Division of Palliative Care, UBC Department of Family Practice
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- Ms Della Roberts, CNS End of Life Care Fraser Health Authority, and Lead for the Workshop and Curriculum development
- Ms Susie Wai, Executive Director, Canadian Strategy for Cancer Control BC/Yukon





## Palliative Approach for Life Limiting Illness – Self-Audit Worksheet

**Instructions:** Randomly select patients from your practice who have a chronic illness and you would not be surprised if they died in the next year. Complete the following worksheet, then read the reference documents outlining palliative approaches to care. Reflect on how your care differed from the recommendations and whether your care could be strengthened in any way. For optimal results, choose patients who have end stage chronic disease (other than cancer).

<b>1.</b> Would you be surprised if your patient died in the next ...	1 yr?    Yes <input type="checkbox"/> No <input type="checkbox"/> 6 mo.?    Yes <input type="checkbox"/> No <input type="checkbox"/> 3 mo.?    Yes <input type="checkbox"/> No <input type="checkbox"/> 1 mo.?    Yes <input type="checkbox"/> No <input type="checkbox"/>
<b>2.</b> This patient is currently: <ul style="list-style-type: none"> <li>• Stable with reasonable function</li> <li>• Declining and needing help with ADL</li> <li>• In the terminal/actively dying phase</li> </ul>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>3.</b> Over the past year, has the patient experienced: <ul style="list-style-type: none"> <li>• Deteriorating functional status</li> <li>• Recurrent hospital admissions</li> <li>• Increasing symptoms despite optimal disease management</li> <li>• &gt; 10% weight loss</li> </ul>	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
<b>4.</b> Have you had discussions regarding the patient's/family's: <ul style="list-style-type: none"> <li>• Understanding of the illness &amp; expected illness trajectory</li> <li>• Goals of care / Preferences and needs</li> <li>• Substitute Decision Maker</li> </ul>	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
<b>5.</b> Have key decisions been made in relation to: <ul style="list-style-type: none"> <li>• acute episodes and crisis events</li> <li>• interventions in relation to declining function</li> <li>• resuscitation</li> <li>• preference for place of end of life care</li> </ul>	Discussion Yes <input type="checkbox"/> No <input type="checkbox"/> Decision Yes <input type="checkbox"/> No <input type="checkbox"/> Discussion Yes <input type="checkbox"/> No <input type="checkbox"/> Decision Yes <input type="checkbox"/> No <input type="checkbox"/> Discussion Yes <input type="checkbox"/> No <input type="checkbox"/> Decision Yes <input type="checkbox"/> No <input type="checkbox"/> Discussion Yes <input type="checkbox"/> No <input type="checkbox"/> Decision Yes <input type="checkbox"/> No <input type="checkbox"/>
<b>6.</b> Has your patient completed an Advance Care Plan	Yes <input type="checkbox"/> No <input type="checkbox"/>

<p><b>7.</b> Are there identified psychosocial issues for the patient?</p> <ul style="list-style-type: none"> <li>• Is the patient socially isolated?</li> <li>• Does the patient (or other person in the home) have a history of substance abuse?</li> <li>• Is there a history of anxiety or depression?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>8.</b> Are there identified issues regarding family or caregiver coping or support?</p> <ul style="list-style-type: none"> <li>• Is the family often anxious or worried?</li> <li>• Are the patient &amp; family in agreement about goals of care</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>9.</b> Did your assessment/workup of the patient include:</p> <ul style="list-style-type: none"> <li>• Did you ask about a range of symptoms?</li> <li>• Location and type of pain?</li> <li>• Intensity of pain on a scale of 0-10?</li> <li>• Did you ask about constipation?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>10.</b> Have you developed a care plan with your patient?</p> <ul style="list-style-type: none"> <li>• Are there scheduled planned patient visits?</li> <li>• Are there identified monitoring parameters?</li> <li>• Does the patient know to report symptom or functional changes?</li> <li>• Is there a plan in place to manage symptoms?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>11.</b> Do you know who are the key health care providers involved with this patient?</p> <ul style="list-style-type: none"> <li>• Have you referred the patient to Home Health?</li> <li>• Have you been in communication with the key provider/s?</li> <li>• Would this patient meet the criteria for Palliative Benefits? <ul style="list-style-type: none"> <li>○ If so, enrolled on Palliative Benefits?</li> </ul> </li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>12.</b> Was consultation with a palliative care physician or team member needed?</p> <ul style="list-style-type: none"> <li>• If needed, was it requested?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>13.</b> Has the patient / family been provided with education or information regarding resources?</p> <ul style="list-style-type: none"> <li>• Has the compassionate care benefit been discussed?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>14.</b> Over the past year, has your patient had ER visits or hospitalizations that could have been anticipated and avoided?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>



<p><b>9.</b> If your patient died at home:</p> <ul style="list-style-type: none"> <li>• Was the patient’s anticipated course and prognosis discussed?</li> <li>• Was an EOL care plan developed with Home Nursing?</li> <li>• Was the No CPR form completed?</li> <li>• Was the expected death at home option discussed with family?</li> <li>• Were family informed of the Compassionate EI program?</li> <li>• Were appropriate supports available?</li> <li>• Home support workers</li> <li>• Hospital bed/equipment/supplies</li> <li>• Did the family know who to call when for support 24/7?</li> <li>• Did you (physician) provide home visits</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>10.</b> Anticipatory prescribing:</p> <ul style="list-style-type: none"> <li>• Were non-essential PO meds discontinued?</li> <li>• Were orders provided for change from the oral route?</li> <li>• Were the number of breakthrough doses of opioid reviewed and the regular opioid dose adjusted accordingly?</li> <li>• Was glycopyrrolate, atropine or scopolamine prescribed for possible secretions?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>11.</b> Was the following present in the final days?</p> <ul style="list-style-type: none"> <li>• Pain?</li> <li>• Dyspnea?</li> <li>• Delirium?</li> <li>• If delirium was present: <ul style="list-style-type: none"> <li>○ Was the cause of delirium considered?</li> <li>○ Was there any attempt made to reverse the delirium?</li> <li>○ Was opioid toxicity considered?</li> <li>○ Was a neuroleptic prescribed?</li> </ul> </li> <li>• If refractory symptoms, was palliative care consultation obtained?</li> </ul>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>12.</b> If the patient did not have adequate supports at home, was referral to the local hospice society arranged?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p><b>13.</b> Was a bereavement call/visit done?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>