

PALLIUM



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## **Looking Back, Looking Ahead: Situating *Pallium* as a Learning-based Agent of Change**

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Stakeholder consultation document circulated in preparation of a collaboratively-developed proposal to Health Canada's National Envelope of the Primary Health Care Transition Fund (PHCTF)

March 2003

### Introduction

This consultation document has been prepared to assist stakeholders in playing a collaborative role in proposal planning for a 3 year, multi-million dollar project to the National Envelope of Health Canada's, Primary Health Care Transition Fund (PHCTF).

In May 2002, the Pallium Project, Project Advisory Council (PAC) endorsed a strategic direction that the Project should continue as a key knowledge and skill development leader and resource. In August 2002, a Letter of Intent (LoI) was prepared to the National Envelope of Health Canada's, Primary Health Care Transition Fund (see Appendix A). Late in 2002, the LoI was selected as one invited for further consideration as a full proposal. In late February 2002, specific direction was provided as to the substance and timing for the full PHCTF proposal.

The Project is currently working with its stakeholders to develop a proposal that helps Canada's health care systems for capitalizing on change and reform, with a clear focus on strengthening primary-care palliative and end-of-life care key supports. Through mid-April 2003, the Project will be working to prepare an application for a three year project which is clearly focused on situating *Pallium* as a learning-based agent of change for system improvement and renewal. We will do this by building on the foundation of our dynamic professional community culture.

### Looking Back: Where We Have Been and Lessons Learned

In February 2001, *Pallium* commenced as a funded activity project, supported by Health Canada's, Rural and Remote Health Innovations Initiative (RRHII) and in-kind contributions of time and energy from palliative care professionals and their respective employing/voluntary agencies. The Project undertook targeted foundation building activities over an 18 month (to Nov 2002) period in:

- Needs assessment (based on the needs, requirements and realities of rural context).
- Teaching-learning materials resource mapping;
- Web-portal development;
- Flexible-delivery learning opportunities (pilots and analysis); and
- Learning module development focused on the needs of community-based, rural health care clinicians.

As the Project evolved, four core roles/purposes for the project emerged:

1. A Canadian clearinghouse, knowledge exchange and Community of Practice (CoP) for efficiently disseminating palliative care knowledge, skills and resources.
2. Coordinate and facilitate the integration of palliative care continuing professional development (CPD).
3. Collaborate among palliative care stakeholders on the adoption/adaptation of existing, and the creation of new, palliative care learning resources.
4. Facilitate strong, collaborative links with practitioners, policy makers, and scholars in palliative care research, public policy, clinical practice and education.

Themes emerging from the summative evaluation of the RRHII project regarding major achievements to-date include:

1. Collaborative development of materials to meet the needs of rural primary-care professionals.
2. Increased awareness of the substantive aspects of providing quality palliative care, and
3. Collective ownership of the process, both in implementing the Project and in moving palliative care teaching-learning beyond design based on a strict medical management model, to one which respects the contributions of many caregivers to the process.

## Looking Back, Looking Ahead: Pallium as a Learning-based Agent of Change

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Three main effects of the Pallium project, as defined by thematic responses arising out of the question *What difference has the project made?*, are:

1. Increased awareness of palliative care, particularly for rural areas.
2. The achievement of access to local learning for rural palliative caregivers.
3. Development of partnerships and collaborations.

Suggestions for “doing things differently” include:

- Improved support for practitioners who serve as teaching-learning resources to peers.
- Designated professional resources in project development, so that professionals involved have dedicated, compensated and clinical coverage assured during their time away from practice.
- Formalize the support and mentoring mechanisms so it is not an “add on” responsibility.

Prospective future directions for the project based on the summative evaluation interviews are:

- Continuation of the processes that have been established (as articulated by words such as “continue” “build” “expand” “further develop” “maintain”, etc.).
- Continue to build on the momentum created by the project, with a special attention given to the “multi-disciplinary, team-based” approach to supporting caregiver learning.
- Support the processes of informal learning in the workplace, with special attention paid to building vehicles for dialogue among professionals, to balance discussions of the “context of care” with “content only” spaces; nurture “dialogue between front-line practitioners, specialists in larger centres, and academics.”

A list of prospective future activities, as suggested during the summative evaluation interview process for the RRHII project, are:

- Continual development, revision, and update of materials and trainers
- Formalize the consulting process and follow-up support mechanisms
- Create education modules for both small and large groups
- Initiate discussions with Professional Associations toward the recognition of competencies through Palliative Care Certification – specialist recognition
- Obtain financial support to continue and expand operations
- Expand work with First Nations
- Provide services in the local language of choice and within cultural variations
- Initiate discussions with educational institutions for healthcare providers to integrate palliative care knowledge gained by the Pallium Project into the curriculum
- Develop an orientation package of palliative care information to integrate into the healthcare orientation for all caregivers
- Develop educational and reference materials that can be used at the bedside – posters, pocket-sized references
- Investigate the integration of Pediatric palliative care into Pallium
- Transfer the knowledge gained in Pallium to their related health issues such as bereavement and chronic pain management
- Operationalize the on-line course
- Expand the education/training material to include other professionals who are involved with palliative care patients – formal informal caregivers, therapists, etc.
- Refine the Telehealth link
- Contribute to Canadian Virtual Hospice
- Evaluate the effect on palliative care practice

Additional lessons learned from our early work with primary, palliative care professionals in rural remote environments include the need to design learning supports which:

- Enables a dual approach for learning and development. That is, one which focuses not only on: a) continued knowledge and skills development to those caring for Canadians with life-threatening and life-limiting illness, BUT ALSO b) using learning-based opportunities to help decision makers identify and commit to those critical success factors necessary for quality palliative care provision. That is, targeted activities are required to enable decision-makers to make informed, prudent decisions about the value of palliative and end-of-life care. In some jurisdictions, this is being called “re-balancing focus”, with an emphasis on “balancing” palliative and supportive care in the context of a dominant curative care paradigm within formalized health care delivery cultures.
- Respects primary caregivers’ roles in dealing with a range of health and wellness issues, and acknowledges the reality that for many, palliative care reflects a “low patient volume” reality that limits their ability to develop knowledge and skills through frequent, repeated practice as a platform for professional learning.

### Looking Ahead: Situating As a Catalyst for Change

In August 2002, the Project submitted a Letter of Intent to the National Envelope of the Primary Health Care Transition Fund (PHCTF). The mandated objectives\* of the PHCTF are to:

- Increase the proportion of the population having access to primary care organizations, accountable for the planned provision of a defined set of comprehensive services to a defined population;
- Increased emphasis on health promotion, disease and injury prevention, and management of chronic diseases;
- Expand 24/7 access to essential services;
- Establish interdisciplinary primary health care teams of providers, so that the most appropriate care is provided by the most appropriate provider; and
- Facilitate coordination and integration with other health services (i.e., institutions and communities).

The specific objectives\* of the National Envelope of the PHCTF are:

- Enhancing the sustainability of the primary health care system by engaging stakeholders and the public in a dialogue on primary health care renewal;
- Educate the public about primary health care renewal;
- Maximize synergies and the use of common/collaborative approaches to renewal by providing for a for information sharing on primary health care renewal experiences;
- Improve the availability and quality of information on primary health care nationally (e.g., evaluation, progress indicators);
- Create common practical tools to address the challenges that will arise during the renewal process;
- Facilitate collaboration among professions involved in primary health care; and
- Facilitate changes to practice patterns for primary health care providers.

Projects must also be of national significance\* and relevance by addressing an issue that affects several different regions of the country. Even if an initiative is only conducted in a few jurisdictions, it must have national applicability (i.e., results or products must be transferable/ useful to other jurisdictions of the country).

\* These sections taken verbatim from the RFP and Application Form for National Initiatives under the PHCTF National Envelope

The declared directions made to Health Canada in the *Pallium* Lol for how the project as a professional community would proceed to a full proposal to the National Envelope include:

- Implement a framework for inter-sectoral (e.g., health services, academic, government, voluntary, etc.) and multi-provider (e.g., formal and informal caregivers, multiple disciplines, etc.) primary, end-of-life care capacity building. The framework will inform, renew and extend end-of-life care by formalizing and integrating linkages with specialty care resources.
- Providing national, shared leadership with key partners for dual-language, multi-provider, end-of-life care learning resources that are sensitive to, and sensible about, the needs and context of primary-care practice.
- Conducting a sub-project with stakeholders in low-resource and isolated northern locales, emphasizing the role of communities and lay community health care workers as full partners with health care professionals in the provision of primary, end-of-life care.
- Acting and leading with key national partners implementing collaborative learning and policy development forums that result in focused, meaningful efforts to improve end-of-life care as an education provider priority and health system development issue.

Within these declared directions, there is considerable flexibility at the proposal development stage for stakeholders to provide input and direction as to how we actually proceed in developing and implementing a plan to achieve these directions, as well as for declaring preferences for specific roles in the process.

### Early Design Considerations

Some early design work has gone into reflecting what kinds of elements or components might be helpful in designing a project that helps to build palliative and end-of-life care capacity in primary care environments. This design work was necessary in the summer of 2002 to arrive at an approximate dollar amount to include in the Lol. It is offered at this time as a starting point for discussion with stakeholders of the *Pallium* professional community.

#### Prospective Vision Statement (taken from Pallium PHCTF Preliminary Design Document)

*Every Canadian formal and informal care provider will have access to needs-based, reliable information and learning support resources, to enable quality palliative care, including end-of-life care and bereavement support, in a way that respects the most effective and affordable place of care, and that maximizes the potential contributions of Canada's health care continuum.*

#### Proposed Values to Guide Design (taken from Pallium PHCTF Preliminary Design Document)

- Respect for each caregivers potential contribution.
- Full-engagement of primary caregivers in palliative care, including end-of-life care and bereavement support.
- Responsiveness to learning supports which are aligned with the realities of the care context.
- Collaboration focused on maximizing potential contributions and minimizing undue duplication.
- Consistency in knowledge and skill transfer and application to the care setting (based on what is known to be effective; what is best or better practices).

#### Preliminary Design Principles (updated from Pallium PHCTF Preliminary Design Document and aligned with emerging directions from Canadian Strategy for Palliative and End-of-Life Care).

- Building, aligning and integrating good work being done by others throughout the nation.

- Pursuing a “Needs-based approach” as defined by the actual requirements of practice (e.g., DACUM).
- Building the capacity of the system to respond to emerging demand (i.e., system readiness)
- Facilitating workplace learning (i.e., experience-based, just-in-time, evidence-supported)
- Facilitating context-based (situational) learning (i.e., getting the job done with what you have).
- Recognizing three levels of need (i.e., individual care giver, team/organization, system).
- Building solutions from evidence-based practice and practice-based evidence.
- Organizing to interface through provincial/territorial and regional clusters/approaches as a unit of delivery and building (i.e., outreach programming).
- Encouraging and leading curricular standards development (e.g., linked to CHPCA Norms of Practice, CNA nursing specialty, etc.) with learning objects “adaptable” to local needs
- Supporting and encouraging a culture of “critically reflective practice” and transform towards quality end-of-life care as an “entrenched core value” of Canada’s health care systems.
- Valuing and promoting a holistic approach (i.e., multiple domains of issues causing suffering and decrease in quality of life), but leading from pain and symptom management as the “hook” for current care givers.
- Promoting innovation in service and program development by activity involving senior decision-makers in learning and development.

### **Potential Key Activities**

In preparing the Lol we considered (but did not commit in the context of the Lol) the following key activities as prospective vehicles for helping achieve the directions to which we committed to in the Lol. They are presented here as a starting point for further discussion. The expected orientation of discussion with stakeholders will be to comment on the following questions:

- Can it work?
- Does it work?
- Will it make a difference?
- Is the approach integrated, appropriate and fundamentally complete (i.e., Anything missing? and/or Are there other ways to do it better and arrive at the same end?)
- What priority ought to be placed on specific key activities?

### Peer-mentoring Initiative

The peer mentoring initiative was initially conceived to see dedicated advanced practice nursing and physician resources located at key academic health sciences centres/palliative care specialty programs, to provide outreach peer-mentoring, just-in-time learning support, and dedicated expert resources in resource development. The intent of this initiative is to formalize and extend the informal activities in which primary-care professionals engage with colleagues at specialty palliative care units. It is intended to support problem-oriented, practice-based learning around specific patient needs, and to use said interactions as the basis to develop knowledge tools and resources to collectively help care givers. This initiative could provide provider supports, including:

- Peer-mentoring and just-in-time learning support (possibly also in partnership with CVH).
- Developing peer-reviewed “Ask the Experts” content (possibly a Canadian version of EPERC’s Fast Facts and concepts, and possibly also in partnership with EPERC and others).
- Providing content expertise and “Course Director” support for Regional Weekend Courses (RWC) and other outreach education.

- Providing leadership in the design and demonstrating of a tele-consulting service that would capitalize on jurisdictions' existing tele-health infrastructure to provide scheduled "in-reach" clinic time in support of Regional Resource Teams.
- Provides content development and editorial assistance in refining and promoting wider adoption of practical, "front-line" palliative care knowledge resources for primary-care professionals (e.g., re-development of *ACB Palliative Care Resource*; *99 Common Questions (And More) About Palliative Care: A Nurses Handbook*).

### Outreach Education and Professional Development Initiative

This initiative is proposed to continue the development of learning resources that provide the opportunity for formal and informal caregivers to meet their learning needs in forms and places that are most appropriate to their context and circumstances. Specific activities that might be included under this initiative, include:

- Full implementation of the Regional Weekend Course (RWC) model, with the goal of ensuring that each health region within the project catchment has the opportunity to have at least one RWC in a three-year rotating cycle, and with the full support necessary to implement a well developed local RWC.
- Topic specific, monthly tele-rounds (a Grand-rounds style presentation based on the approach pioneered by the Regional Palliative Care Program of Lakeland Regional Health Authority).
- Outreach education focused on supporting informal caregivers in caring for loved ones in the community (e.g., possibly based on the PCAA's *A Caregiver's Guide*)
- Full implementation and support of a range of flexible-learning opportunities, including an *Introduction to Palliative Care* web-based course and special interest Online Journal Club sessions and Moderated Discussion Forum (e.g., pharmacy updates, psycho-social, family practice updates, palliative home care nursing practice and management updates, etc.).
- Construction of an online "Knowledge Commons" (based on the pioneering work being done in other professions) to support certification exam preparation and just-in-time, workplace learning (i.e., *Ask the Experts*).
- Structured learning experiences for those wishing to pursue their interest in palliative care on a flexible-delivery basis, leading to earning of a college or university-based certificate.

### Palliative Care Leadership and Service Development Initiative

This Initiative might include activities such as:

- *Service Leader's Executive Briefing and Round Table Exchanges* - to sensitize, create awareness, and identify specific pathways for re-balancing focus in integration of palliative care, including end-of-life care and bereavement support, as an essential component of state-of-the-art population-health based, primary care systems.
- *Service Development Institutes* – focused on service and program development issues, with special emphasis on developing Regional Resource Teams (RRTs) that provide direct support to primary care-givers and that work with peer-mentors to develop local knowledge and skills.
- *Local Program Development Project* – focused on developing tools and resources (e.g., templates, indicators, surveillance approaches) to help local leaders better manage and develop their programs in coordination with other emerging initiatives (e.g., palliative home care), so that the integrity of integrated approaches to hospice palliative care is maintained, sustained and further enhanced.

### Collaborative Development Initiative

Template and provincial/territorial resources and institutes focused on building voluntary sector capacity at the community-level in ways that are managed and integrated with primary care as supported and funded within formal delivery systems. The intent of this initiative is to put in place some of the structural catalysts required to enable the evolving vision of a fully-integrated hospice palliative care approach in western and northern Canada.

### Provincial/Territorial Community-based Grief and Bereavement Support Programs

This initiative is focused on collaborating with the provincial associations to provide community-level leadership in making grief and bereavement support widely available.

### Web-based, online Community of Practice (CoP) and “Knowledge Commons”

This initiative is a specific infrastructure requirement necessary to enable the outreach education and professional development initiative.

### Other-than-Cancer (OTC) Palliative Care Resource Development Initiative

This initiative respects the strong heritage of palliative care leadership and development in Canada evolving from oncology specialty services, while recognizing that quality end-of-life care in Canada involves building learning resources and supports a range of expected life-limiting circumstances, including (known order of expected death occurrences):

- Cancer-related illness (expected to markedly increase by 2015)
- End-stage organ failure (i.e., heart, lung, renal as leading occurrences)
- Neurological illness (e.g., Multiple Sclerosis, ALS)
- Immunologic illness (e.g., AIDS)

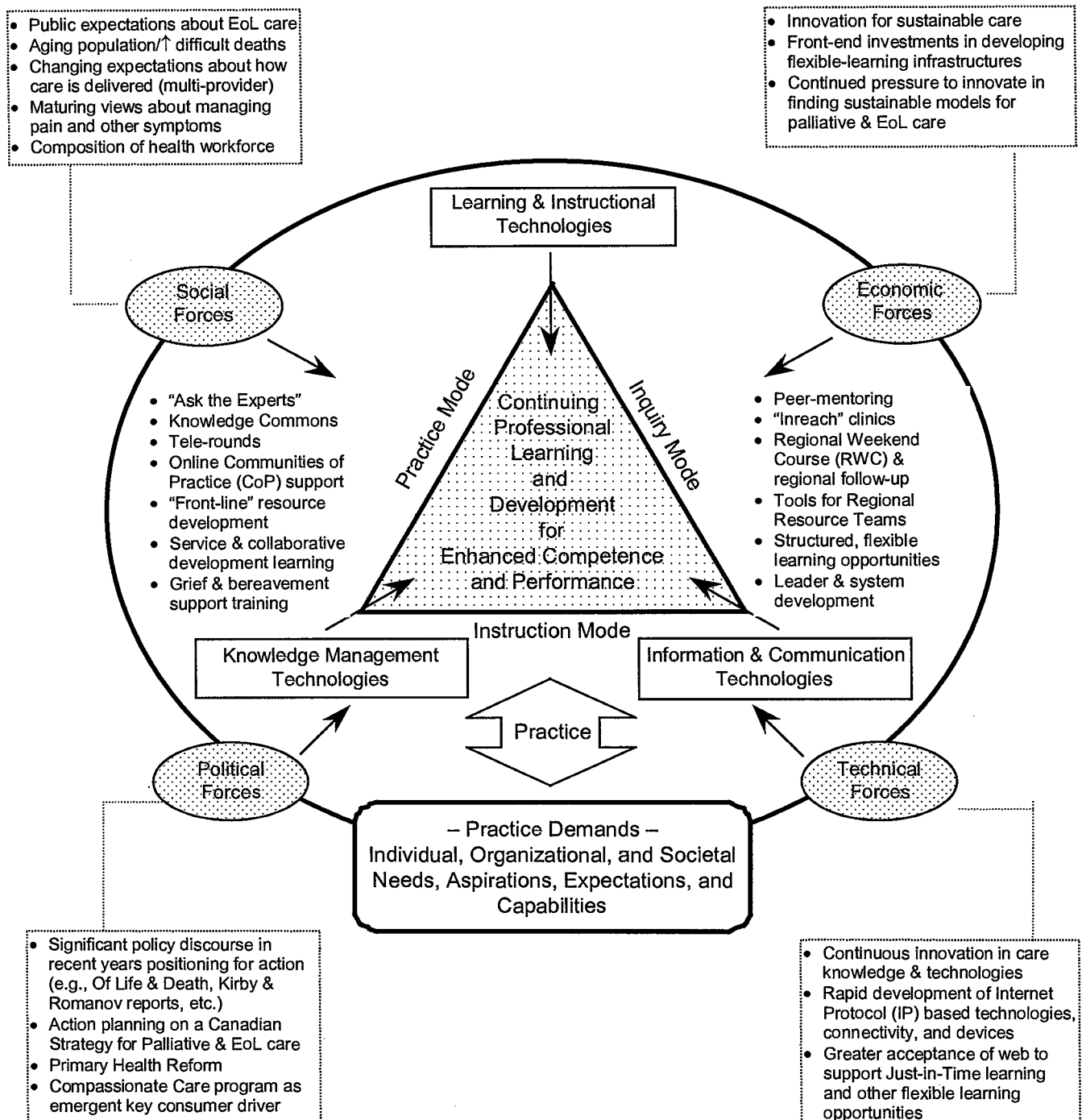
This initiative would focus on linking known knowledge around specific end-stage disease modalities and focus said knowledge with current “best” integrated care management practices in learning resource packages (e.g., workshop facilitators guide, participant handbook, video, web-links at Knowledge Commons, etc.).

### Proposed General Approach

Much of the learning content and the essential foundations to enable prospective initiatives discussed above has been piloted by leaders in specialty programs, existing initiatives, and provincial-level voluntary associations. Many of these organizations are listed as current partners or expected partners in the last section of the Lol. Our proposed general approach to resource development is to pioneer a model of resource licensing which would essentially enable previous development innovations and/or content to be further developed or expanded for broader inter-jurisdictional or national application. Hence, to enable working collaborations, Pallium will develop a model for *Functional Partnerships* and *Relational Partnerships* that will allow the further and reasonable development of sustainable palliative care resources, based on the innovative early work of various partners throughout the country.



Graphical Overview of Early Project Design Directions Based on An Integrated Approach to Continuing Professional Development in Palliative Care



## **APPENDIX A**

### **Letter of Intent Submitted for Consideration under the National Envelope of the Primary Health Care Transition Fund (PHCTF)**

**August 14, 2002**

# Letter of Intent for Primary Health Care Transition Fund (Lol) PALLIUM Integrated Care Capacity Building Initiative (Canada West and North)

## Description

There is consensus among government and non-governmental stakeholders on priorities for action to improve palliative and end-of-life care in Canada. Increased education and training for health care providers has been identified as a priority area in two Senate Committee reports (*Of Life and Death*, June 1995) and (*Quality End-of-Life Care: The Right of Every Canadian*, update *Of Life and Death*, June 2000). This priority is also made clear in the Quality End-of-Life Care Coalition's *Blueprint for Action* (2001) and from the results of a March 2002 Health Canada hosted national action planning workshop.

This proposed 3-year initiative will implement a framework to enable workplace learning and build system capacity through formalizing integrated linkages amongst primary, secondary and tertiary-level palliative and end-of-life care. It will focus on practitioner and system-leader awareness, knowledge, skills, tools, and functional partnerships to rapidly advance multi-provider, end-of-life care. It will do this through an established multi-stakeholder, inter-sectoral initiative called The PALLIUM Project. PALLIUM has its roots in a Health Canada supported "proof-of-concept" innovation project in rural/remote palliative care workplace learning and capacity enabling.

The initiative will build on the results of PALLIUM, furthering the work, and capitalizing on robust collegial, organizational, and inter-jurisdictional networks. Strategic outcomes-to-date include:

1. Ongoing, systematic analysis of practice-based learning and system-enabling needs;
2. Mapping of best-available palliative and end-of-life care teaching-learning materials, and current best-evidence in palliative and end-of-life care education research;
3. Developing a first-generation, online learning lab and conducting applied health systems research;
4. Developing a model to support integrated, multi-professional, workplace learning.

The initiative will focus on key enablers for quality end-of-life care in British Columbia, Yukon, Alberta, NWT, Saskatchewan, Manitoba and Nunavut. It will also use functional, national partnerships in critical areas (e.g., workplace-based, clinical learning resources in both official languages; action-learning based, national education and system development; community capacity building resources, etc.). The strategic intent is for primary and tertiary care to build capacity through formal, integrated linkages for Quality End-of-Life Care regionally, based on a process of in-reach, outreach and collaboration. And where information and curriculum is required to support workplace-learning and care-based decision making, to approach this through national collegial networks to assure resources developed for one region have national application.

The project has national significance and relevance as a framework in a large geographic region (7 of 13 provincial/territorial jurisdictions) that is transferable. It also has national significance in its interface with established partners for "on-demand" clinical information and facts, and flexible learning opportunities for busy and/or isolated primary-health care providers. It is further positioned for a national role in assisting key national partners in public education and toolkits for community asset building. This project supports priorities under the national envelope in the following ways:

## Key areas

- Implementing a framework for inter-sectoral and multi-provider primary, end-of-life care capacity enabling in western and northern Canada that is synergistic, portable and scalable. The framework will inform, renew and extend end-of-life care by formalizing and integrating linkages with secondary and tertiary resources - especially in regional health authority (RHA) based health delivery systems, where structural funding disincentives for inter-regional collaboration exist.
- Providing national, shared leadership with key partners for dual-language, multi-provider, end-of-life care teaching-learning (e.g., curricula) and care-based/clinical decision support tools that are sensitive to, and sensible about, the needs and context of primary-care practice.

- Conducting a sub-project with stakeholders in low-resource and isolated northern locales. This will focus on how to better enable capacity that is locally, culturally and resource sensible (e.g., aboriginal communities), and emphasize roles for communities and lay community health workers as full partners with health care professionals in provision of primary, end-of-life care.
- Acting and leading with key national partners in implementing collaborative learning and policy development forums that result in focused, meaningful efforts to improve end-of-life care as an education provider priority and health system development issue.

## Key Implementation Partners \*

Alberta Cancer Board  
 Palliative Care Network Initiative  
 Palliative Care Research Initiative  
 ACB Research Administration  
 TBCC Centre for Distance Learning  
 Canadian Virtual Hospice (CVH) initiative  
 CancerCare Manitoba  
 Health Canada  
 Palliative and End-of-Life Care Secretariat [E]  
 Centre for Chronic Disease  
 Prevention and Control [E]  
 University of Alberta  
 Division of Palliative Medicine  
 Institute for Professional Development  
 Div of Continuing Medical Education  
 Department of Family Medicine  
 Faculty of Nursing  
 School of Native Studies [E]  
 University of British Columbia  
 Division of Palliative Medicine [E]  
 Div of Continuing Medical Education [E]  
 University of Calgary  
 Division of Palliative Medicine  
 Faculty of Continuing Education  
 Learning Commons Department  
 Office of CME and Prof Development  
 University of Manitoba  
 Department of Family Medicine  
 Section of Palliative Medicine  
 Northern Health Unit [E]  
 Division of Continuing Education  
 University of Regina  
 College of Social Work [E]  
 University of Saskatchewan  
 Palliative Medicine Program  
 College of Nursing  
 Department of Extension  
 Department of Geography [E]  
 Grant MacEwan College, Palliative Nursing Program [E]

Ian Anderson Program in End-of-Life Care Continuing Education, University of Toronto  
 Lakehead University/Laurentian University,  
 Centre for Rural & Northern Health Research [E]  
 Memorial University of Newfoundland (MUN), The Electronic Rural Medicine Strategy (TERMS) project  
 Canadian Hospice Palliative Care Association [E]  
 Canadian Nurses Association,  
 Palliative Care Nursing Interest Group [E]  
 Canadian Oncology Nurses Association [E]  
 Canadian Society of Palliative Care Physicians [E]  
 College of Family Physicians of Canada [E]  
 British Columbia Hospice Palliative Care Association [E]  
 Palliative Care Association of Alberta  
 Saskatchewan Palliative Care Association  
 Hospice & Palliative Care Manitoba

### Health Service Partners

Manitoba Palliative Coordinator Network & RHAs  
 Sask. Palliative Coordinator Network & RHAs  
 Calgary Health Region  
 Capital Health Authority (Edmonton)  
 Regina Health District  
 Saskatchewan Health District  
 Winnipeg Regional Health Authority  
 Inuvik Regional Health & Social Service Board  
 Stanton Regional Health Board (NWT)  
 Chinook Health Authority (Alberta)  
 David Thompson RHA (Alberta)  
 East Central Health (Alberta)  
 Lakeland RHA (Alberta)  
 Yukon palliative care committee [E]

\* Current PALLIUM partner unless identified with an [E] denoting Expected Partner with a commitment of confirmed partnership statement (i.e., role, responsibilities, relationship, resources) at time of submission of full PHCTF proposal.

## Time Frame and Budget

The time frame is for a focused, three-year initiative commencing 2003 (subject to timing of Health Canada decision/announcements) and executed with a project management approach. We estimate a minimum of \$1.4 million/year will be required (including evaluation research at 10% and excluding in-kind contributions from partners and collaborators) for the initiative.